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Long-term dementia care: staff experiences and family satisfaction

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This thesis is submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology

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List of Abbreviations

| | |
|---------------|--|
| ADLs | Activities of Daily Living |
| ASC | Alzheimer's Society of Canada |
| BPS | British Psychological Society |
| CINAHL | Cumulative Index to Nursing and Allied Health Literature |
| CQC | Care Quality Commission |
| DOH | Department of Health |
| IPA | Interpretative Phenomenological Analysis |
| NICE | National Institute for Health and Care Excellence |
| NHS | National Health Service |
| NVQ | National Vocational Qualification |
| PRISMA | Preferred Reporting Items for Systematic Reviews and Meta-Analyses |
| PwD | People with Dementia |
| PwLD | People with Learning Disabilities |
| UK | United Kingdom |
| USA | United States of America |

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Declaration

This thesis has not been submitted for any other degree or to any other institution. The research was conducted under the academic supervision of Dr Tom Patterson (Academic Director, Coventry and Warwick Clinical Psychology Doctorate) and the clinical supervision of Jane Muers (Clinical Psychologist). Both supervisors helped me to develop my initial research ideas and provided suggestions and feedback throughout the research process. They also read drafts of the chapters. One of my colleagues, along with both supervisors, who were all familiar with Interpretative Phenomenological Analysis, were involved in validating my coding. Furthermore, another colleague was involved in checking the validity of my quality appraisal ratings. Apart from these collaborations, this thesis is my own work.

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Chapter 2: 7999

Chapter 3: 4000

TOTAL: 19998

Summary

This thesis focuses on the care of people with dementia in long-term care settings. It considers both the experiences of staff working with people with dementia in such settings as well as the perceptions and satisfaction of family members of people with dementia who reside in long-term care. It is hoped that these papers will contribute to understanding how staff working with people with dementia in long-term care settings can be supported to improve the quality of care provision to this population.

Chapter 1 is a systematic literature review investigating the staff factors which contribute to family satisfaction with ongoing care provision for their relatives with dementia who reside in long-term care. Empirical evidence from 14 articles was critically evaluated in order to identify relevant staff factors which contribute to family satisfaction. Relevant staff factors in three broad areas were found to contribute to family satisfaction with care provision for their relatives with dementia. Each area is explored and consideration is given to the implications for future research and clinical practice.

Chapter 2 is an empirical study exploring the lived experience of healthcare assistants working with clients with dementia in residential care homes. Interpretative Phenomenological Analysis was used to analyse the data derived from semi-structured interviews with eight healthcare assistants. Three superordinate themes and nine subordinate themes emerged following the data analysis. Each theme is explored and consideration is given to the implications for future research and clinical practice.

Chapter 3 is a reflective account of the researcher's personal experiences of working with people with dementia. It explores the change in the researcher's perceptions and attitude towards working with people with dementia as their knowledge and experience has increased over time and the impact that this has had on their outlook regarding working with people with dementia in the future.

Chapter 1: Literature Review

Staff factors contributing to family satisfaction with long-term dementia care: A systematic review of the literature.

In preparation for submission to *Dementia* (See appendix A for author instructions)

Overall chapter word count (excluding tables, figures and references): 7999

1.1 Abstract

The aim of the present review was to critically evaluate empirical evidence regarding staff factors that contribute to families' satisfaction with ongoing care provision for their relatives with dementia in long-term care. Four databases were systematically searched using search terms informed by the aim of the present literature review. The resulting 14 relevant articles comprised both qualitative and quantitative studies. The findings highlighted three broad areas relating to staff factors which appeared to contribute to families' satisfaction with care provision: family related factors, which related to how staff interacted with families themselves; staffing related factors, which focussed on the organisation and composition of staffing; and client related factors, which focussed on how staff interacted with clients and the quality of care provided. The findings have important clinical implications for care staff and managers working in such settings regarding staffing organisation, staff training, recruitment and retention. Future research directions are discussed.

Key words: Dementia, families, long-term care, satisfaction, staff factors

1.2 Introduction

1.2.1 Person-Centred Dementia Care

In the United Kingdom (UK), a number of recent high profile reports have emphasised the importance of high quality care provision and the need to protect vulnerable people from abuse within long-term care settings (e.g. Department of Health (DOH), 2012). This has included people with dementia (PwD) residing in such facilities (e.g. Care Quality Commission (CQC), 2013). The CQC have recently outlined their determination to help ensure that PwD receive high-quality care, arguing that a personalised approach is key (CQC, 2014). Person-centred care has been defined as “a philosophy that recognizes that individuals have unique values, personal history and personality and that each person has an equal right to dignity, respect, and to participate fully in their environment” (Alzheimer’s Society of Canada (ASC), 2011, p.10). It has been argued that four main principles of person-centred care underpin good practice when working with PwD (National Institute for Health and Care Excellence (NICE), 2006). These principles focus on the human value and individuality of PwD and the importance of valuing their own perspective and their relationships and interactions with others (NICE, 2006).

In addition, person-centred dementia care emphasises the importance of considering the needs of family members of PwD and in particular, how to support and enhance their input to their relative (NICE, 2006). It has been recognised that families play an integral role in helping to ensure that PwD have “good days” whilst residing in long-term care, as they help to maintain normality and continuity for the person, while also educating staff about their relative (ASC, 2011, p.33). Indeed,

guidelines for person-centred care in care homes for PwD state that staff should encourage and support families to be involved and engaged in the life of their relative and should treat them as valued members of the care team (ASC, 2011).

However, recent guidance acknowledges that there is only limited evidence regarding how best to support families of PwD and further research to better understand their care provision needs has been recommended (DOH, 2015). In order to provide person-centred long-term dementia care which recognises and supports the needs of families, it is essential to understand both their perspective on the care provided to their relative and the factors that contribute to their satisfaction with care provision.

1.2.2. Family Satisfaction with Long-Term Dementia Care

Previous research has explored families' overall satisfaction with care provision for their relatives with dementia in long-term care. For example, Janzen and Warren (2005) examined family satisfaction with different aspects of care over time. They found that, overall, family members reported high satisfaction initially which remained high over time (Janzen & Warren, 2005). Nevertheless, other studies have reported less favourable satisfaction. For example, in one study evaluating family perceptions of an Alzheimer's unit families were less satisfied with nursing care than with care provided by other professionals and were most dissatisfied with not being asked to participate in their relative's care, staff availability and the variety and number of activities available (Maas, Buckwalter & Kelley, 1991).

Furthermore, quantitative studies have attempted to ascertain which factors in particular appear to contribute to families' overall satisfaction. For example, Levy-Storms and Miller-Martinez (2005) examined the relationship between family caregiver's involvement and their satisfaction with care. At admission, more depressed family caregivers and those who provided assistance to their relative with activities of daily living (ADLs) reported lower levels of satisfaction; and one year after admission those providing assistance with ADLs and who perceived their relatives to have behavioural problems were less satisfied with care (Levy-Storms & Miller-Martinez, 2005).

1.2.3 Family Perceptions of Long-Term Dementia Care

Whilst quantitative literature has attempted to evaluate which factors contribute to families' satisfaction, due to the nature of the methodology these studies employ it has not been possible to explore why these factors are important. Studies utilising qualitative methodology have attempted to fill this gap by exploring families' perceptions of the care of their relatives with dementia in long-term care. Previous qualitative literature in this area has tended to focus in particular on families' experiences of the transition to long-term care and end of life care. Indeed, two literature reviews have synthesised literature in these areas.

Firstly, Hennings, Froggatt and Keady (2010) conducted a literature review to explore family carer's knowledge and experiences of end of life care for their relatives with dementia in care homes. They found that families felt unknowledgeable about the process of dying with dementia and wanted staff to explain what has happening and to discuss treatment options. However, families

reported that communication between themselves and staff was either poor or non-existent at a time when they wanted frequent contact and for staff to demonstrate understanding and empathy and to provide reassurance and guidance (Hennings et al., 2010). The authors concluded that the evidence indicated that families seek communication, guidance and companionship from staff at a time when they are simultaneously grieving and caring for their relative; but argued that further research is needed in order to better understand families' needs (Hennings et al., 2010).

A further literature review recently conducted by Graneheim, Johansson and Lindgren (2014) synthesised the literature on families' experiences of relinquishing the care of their relative with dementia to a nursing home. They found this was a unique experience for families but likened it to a crisis process which begins with a turning point and progresses through a coping phase to the eventual outcome. As part of this process they found that families adjusted to a new role as a spokesperson for their relative and monitored the care staff provided. Some families described well-functioning relationships with staff whilst others highlighted difficulties in communication and interaction (Graneheim et al., 2014). The authors concluded that the process of PwD and their families adapting to long-term care can be facilitated if staff recognise families as partners in care (Graneheim et al., 2014).

1.2.4 Staff Factors and Family Satisfaction with Care Provision

These aforementioned literature reviews indicated that several staff factors seemed to contribute to families' overall satisfaction with care provision. Staff

factors contributing to families' overall satisfaction are important to consider because it is these factors over which care home managers and dementia policy advisors have some control. For example, family satisfaction with staff factors may be improved through staff education and training or through the provision of clinical supervision. Given that considering how to enhance and support the input families give to PwD is recognised as an important part of person-centred care (NICE, 2006), it seems pertinent that staff factors contributing to families' overall satisfaction with care are further explored.

1.2.5 Rationale for Present Review

Two previous literature reviews focusing on the experiences of family members of PwD residing in long-term care have been conducted (Hennings et al., 2010; Graneheim et al., 2014). Both reviews focused on specific periods of transition during the time PwD may spend in long-term care: the initial transition period of moving in to a care home and the end of life. Although both considered staff factors that may contribute to family satisfaction with care, families may have unique needs and expectations of staff at these particular points of transition and therefore different staff factors may be relevant to family satisfaction outside these two specific periods. Given the salience of staff factors to both client care and family satisfaction with that care, a review of the empirical literature focussing more broadly on studies of staff factors that contribute to families' satisfaction with the ongoing care provided to their relative with dementia appears to be warranted. This will be the focus of the present literature review.

1.2.6 Aim

The primary aim of the present literature review was to critically evaluate the existing empirical evidence regarding staff factors that contribute to families' satisfaction with the ongoing care provided for their relatives with dementia in long-term care. Both qualitative and quantitative literature that fulfilled the inclusion criteria were considered, providing that findings were reported on staff factors that may potentially contribute towards families' satisfaction with care provision.

1.3 Method

1.3.1 Search Strategy

1.3.1.1 Database Search

A systematic literature search was conducted to identify relevant journal articles. The following bibliographic databases were searched: PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Scopus and MEDLINE. Each search was performed using the search terms outlined in table 1.1. The search was not confined to a specific time period; although articles published after January 2015 were not considered.

| |
|---|
| <p>(dementia OR Alzheimer*)</p> <p>AND</p> <p>(spouse OR famil* OR caregiver* OR carer* OR relative*)</p> <p>AND</p> <p>(experience* OR view* OR opinion* OR perception* OR perspective* OR attitude* OR outlook OR stance OR account* OR satisfaction OR dissatisfaction)</p> <p>AND</p> <p>("care home*" OR "care facility*" OR "residential home*" OR "residential care" OR "nursing home*" OR "nursing care" OR "long term care" OR "long-term care" OR "group living" OR "group home*" OR "homelike facilit*" OR "specialised care" OR "specialized care" OR "group home living")</p> |
|---|

Table 1.1: Database search terms

The title of each reference generated was screened to assess its relevance. Those obviously unrelated to the review aim were discarded. The abstract of each potentially relevant reference was then screened. If further clarification was necessary the full article was located and screened against the inclusion and exclusion criteria outlined in table 1.2.

1.3.1.2 Manual Search

The reference list of all relevant articles was manually searched to identify any additional articles. In accordance with the search strategy above the titles and abstracts of these articles were screened against the inclusion and exclusion criteria in order to assess their relevance to the review. For those deemed potentially

relevant, the full article was located for consideration. Although several full articles were accessed and considered, none fulfilled the inclusion criteria and therefore no further relevant articles were obtained via the manual search.

1.3.2 Selection Criteria

Each article obtained following the systematic search was assessed against the inclusion and exclusion criteria outlined in table 1.2.

| Inclusion Criteria | Exclusion Criteria |
|---|---|
| <ul style="list-style-type: none"> • Studies which report on the perceptions of family members whose relatives have dementia • Studies which report on the perceptions of family members whose relatives reside in long-term care (e.g. nursing homes, residential homes) • Studies in which staff factors feature centrally in the results section of the article • Studies in which relevant staff factors as perceived by family members of people with dementia are clearly identifiable in the results section • Studies which have been published in peer-reviewed academic journals • Studies published in English | <ul style="list-style-type: none"> • Studies which report on the perceptions of family members whose relatives attend day care or respite care rather than residing in long-term care • Studies in which staff factors are only a peripheral focus of the article • Studies in which it was not possible to separate data from family members of people with dementia from data gathered from staff members working with people with dementia or from people with dementia themselves • Studies in which the transition from living in the community to long-term care was the central focus of the research • Studies in which end of life care was the central focus of the research |

Table 1.2: Article Inclusion and Exclusion Criteria

1.3.3 Search Results

14 articles met the criteria for inclusion into the present review. Figure 1.1 outlines the study selection process in line with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, Altman & The PRISMA Group, 2009).

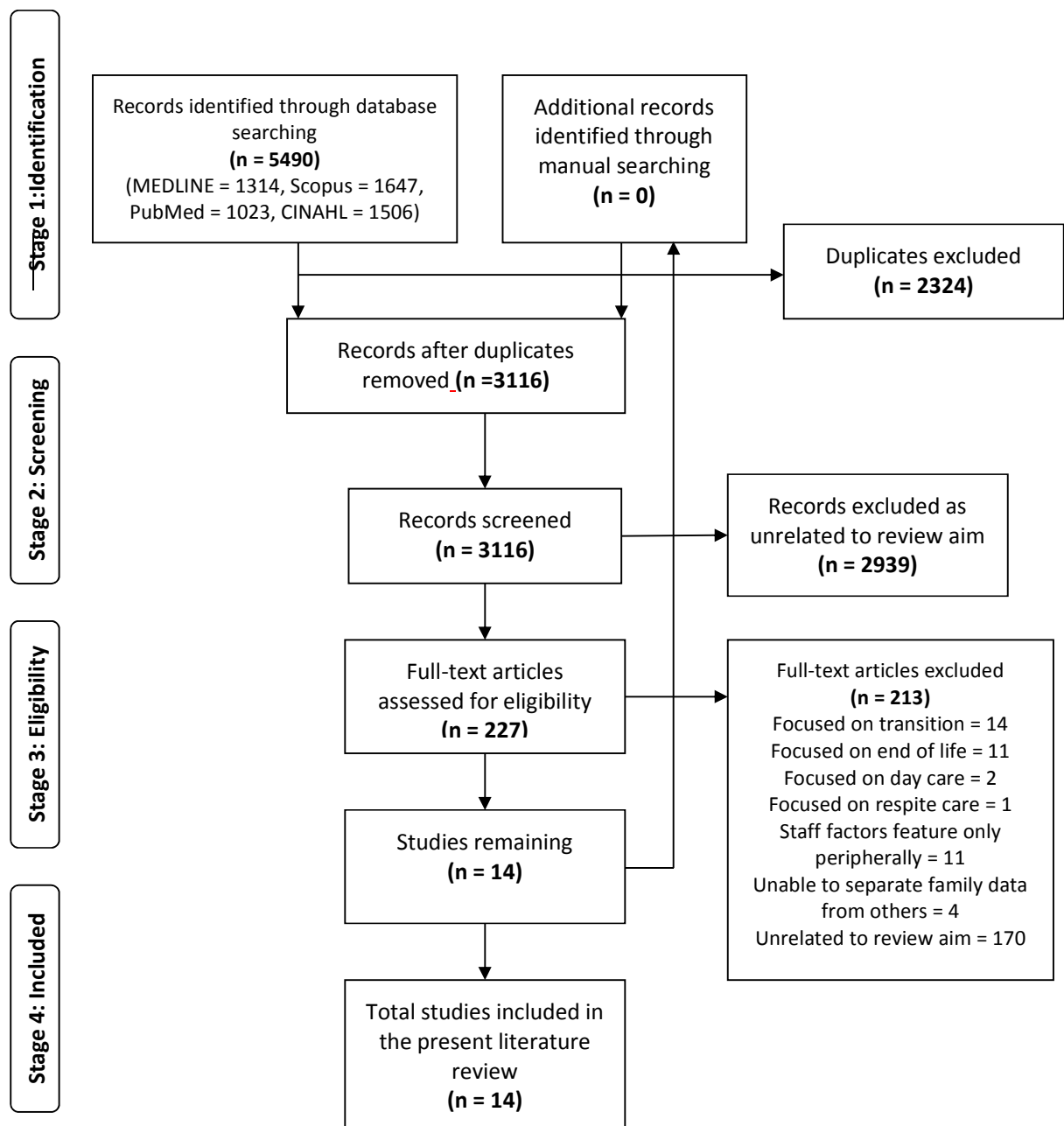


Figure 1.1: An adapted PRISMA flow diagram of the study selection procedure (Moher et al., 2009)

1.3.4 Assessment of Quality

1.3.4.1 Quality Checklist

The final 14 articles included in the present review were appraised using a quality checklist developed by Caldwell, Henshaw and Taylor (2005) and specifically designed to provide a framework for critiquing health-related research incorporating both quantitative and qualitative methodology (appendix B). This checklist was chosen due to the review topic and the inclusion of both qualitative and quantitative research. Although there is some debate about the usefulness of quality checklists, it is recognised that they can be valuable in helping to guide the critical appraisal of studies. For example, it has been suggested that quality checklists for qualitative research “can strengthen the rigour of qualitative research only if they are embedded in a broad understanding of qualitative research design and data analysis” (Barbour, 2001, p. 1117). Therefore, the quality scores obtained in the present review were considered tentatively and were used to highlight each study’s strengths and limitations to aid in the critical evaluation of the data rather than as a basis for inclusion or exclusion into the review.

1.3.4.2 Quality Appraisal Results

All 14 studies were rated according to the above quality checklist (appendix C). Each study was rated on eighteen quality criteria and judged to have either met the criterion (2 points), partially met the criterion (1 point) or not met the criterion (0 points). The score obtained for each criterion was summed to yield a total score out of a maximum 36 points. To enhance the reliability of the ratings two studies were

independently rated by another researcher and the scores were compared and discussed. Statistical analysis to determine inter-rater reliability using a Kappa coefficient revealed a perfect agreement in the ratings for one study (i.e. it was not possible to generate a Kappa coefficient), whilst for the other study there was a two-point difference in ratings, yielding a Kappa coefficient of $k = .550$, $p = .005$ (95% CI: .121 - .979) which indicates a moderate level of agreement (Landis & Koch, 1977).

1.3.5 Critical Analysis of Studies

1.3.5.1 Overview

Thirteen studies scored between 25 and 36 out of a maximum 36 points, demonstrating reasonably consistent high ratings on the quality indicators. One study scored 9 (Shields Scott, 1991) indicating substantial weaknesses. It was a relatively brief paper, which may account for the absence of information relevant to a number of the quality checklist criteria. Nonetheless it was retained due to its relevance to the aim of the present review, though its findings should be interpreted with caution in the absence of a more robustly designed replication study. The general characteristics of each study are presented in table 1.3 (only participant and result details relevant to the present review are presented).

Table 1.3: Characteristics of the studies reviewed

| Author, year of publication, country of origin and quality checklist score | Aims, research questions and topics covered or dependent and independent variables | Sample size, participant details: gender, age, ethnicity and relationship to person with dementia | Recruitment strategy and location | Data collection and data analysis | Key findings |
|---|--|---|---|--|--|
| <p><u>Author:</u> Bramble, Moyle & McAllister</p> <p><u>Year of publication:</u> 2009</p> <p><u>Country of origin:</u> Australia</p> <p><u>Quality checklist score:</u> 32/36</p> | <p><u>Aim:</u> To provide in-depth descriptions of the experiences of family caregivers when placing their relative with dementia in long-term care</p> <p><u>Research question:</u> What does it mean to be a family caregiver of a relative with dementia who is placed in Long Term Care?</p> <p><u>Topics covered:</u> -Caregiving prior to placement -The process and feelings associated with placement -Perceptions of the care relationships with staff -Evaluation of the care facility</p> | <p><u>Sample size:</u> N = 10</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Not specified</p> <p><u>Gender:</u> Male = 3, Female = 7</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Spouse = 3, Child = 7</p> | <p><u>Recruitment strategy:</u> Purposive sampling</p> <p>Managers at two long-term care study sites assisted in identifying family caregivers who were invited by postal invitations, on-site information sessions and via telephone</p> <p><u>Location:</u> Brisbane, Australia</p> <p>Participants recruited had relatives with dementia living in a range of long-term care settings (hostel, nursing home or dementia special care unit)</p> | <p><u>Data collection:</u> Descriptive qualitative approach with semi-structured interviews</p> <p>Questions designed so participants could tell their story and voice their views. Questions were worded to elicit knowledge based on experience and feelings</p> <p>Interview length averaged one hour and was conducted at the long-term care setting or the participant's home</p> <p><u>Data analysis:</u> Not explicitly specified. Major topics were summarised and coded for comparison across participants and the identification of themes</p> | <p>Four themes emerged:</p> <p><i>-Increasing burden and isolation:</i> related to families' experiences of a recurrent pattern of increasing burden of care and a sense of isolation as they lost social contact prior to their relative's admission</p> <p><i>-Relentless grief:</i> related to the loss, sadness and guilt families experienced after their relative's admission</p> <p><i>-Seeking connection and meaning with staff:</i> related to how families experienced their relationships with staff</p> <p><i>-Looking after the person:</i> related to families' perceptions regarding the care provided to their relative</p> |
| <p><u>Author:</u> Duncan & Morgan</p> <p><u>Year of publication:</u> 1994</p> | <p><u>Aim:</u> To understand family caregivers' perspectives on the nature of family-staff relationships in formal care</p> <p><u>Research questions:</u> -What staff did family</p> | <p><u>Sample size:</u> N = 179</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Average age 62 (range 33-87)</p> | <p><u>Recruitment strategy:</u> Method not specified</p> <p>Participants were recruited via post to the Alzheimer's Disease Association contact list, visits to local support</p> | <p><u>Data collection:</u> 30 focus groups each comprising of four to nine participants and lasting approximately 45 minutes</p> <p>10 individual interviews</p> | <p>Results were presented in terms of three main areas:</p> <p><i>-Categories of staff mentioned:</i> Participants made both positive and negative statements about nursing staff, administrative staff, aides and the facility</p> |

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| <p><u>Country of origin:</u> United States of America (USA)</p> <p><u>Quality checklist score:</u> 31/36</p> | <p>caregivers mention most often?</p> <p>-Which staff behaviours were most important to them?</p> <p>-How did family caregivers interpret and evaluate staff behaviours?</p> <p><u>Topics covered:</u></p> <p>-What makes caregiving easier or harder for family caregivers</p> <p>-How the kind of caregiving family caregivers do at home differ from the kind of caregiving that they do when their relative is in a formal care setting</p> <p>-Experiences of contact with staff including the staff behaviours most important to them and how they evaluated staff behaviours</p> | <p><u>Gender:</u> Male = 25%, Female = 75%</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Spouse = 76, Child = 103</p> | <p>groups and contacts with formal care settings</p> <p><u>Location:</u> Greater Portland, Oregon</p> <p>Specific details about the long-term care facilities in which participant's relatives resided was not specified.</p> | <p>with 4 adult children and 6 spouses from the original study</p> <p>A non-directive approach to interviewing was used to allow participants to pursue topics of most importance to them</p> <p><u>Data analysis:</u> Qualitative version of content analysis whereby transcripts were coded based on positive or negative references to staff and then summarised to obtain themes that relate to the staff behaviours most likely to generate positive and negative comments. An Ethnograph software package was used.</p> | <p>staff in general</p> <p><i>-Most important staff behaviours:</i> Participants mentioned staff behaviours such as their relationship with client, their relationship with families and their approach to technical tasks</p> <p><i>-How staff behaviours were interpreted and evaluated:</i> The quality of care staff delivered to their relative mattered most in terms of their interpretations and evaluations of staff behaviour</p> |
| <p><u>Author:</u> Edvardsson, Fetherstonhaugh & Nay</p> <p><u>Year of publication:</u> 2010</p> <p><u>Country of origin:</u> Australia</p> <p><u>Quality checklist score:</u> 33/36</p> | <p><u>Aim:</u> To describe the content of person-centred care as described by people with dementia, their family members and staff in residential aged care</p> <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u></p> <p>-What person-centred care was perceived to be</p> <p>-The meaning of high-quality or low-quality care in residential</p> | <p><u>Sample size:</u> N = 12</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Not specified</p> <p><u>Gender:</u> Not specified</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Not specified</p> | <p><u>Recruitment strategy:</u> Convenience sampling</p> <p>A flyer was put in the Alzheimer's Australia newsletter and interested people who had experience of public or private residential aged care responded by telephoning the researcher</p> <p><u>Location:</u> Victoria, Australia</p> | <p><u>Data collection:</u></p> <p>Face-to-face interviews with those living in metropolitan areas in their own homes</p> <p>Phone interviews with those living in rural areas</p> <p>Interviews lasted between 45 minutes to 2 hours. No details about the interview approach were specified except that the qualitative approach was used to</p> | <p>The core of person-centred care was experienced as promoting a continuation of self and normality, with 5 categories identified as contributing to this:</p> <p>-Knowing the history, preferences, interests and particularities of the person</p> <p>-Family members being welcomed into the life and care of the person</p> <p>-Meaningful activities that were adapted to the person's ability level</p> <p>-Being in a personalised environment</p> |

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| | <p>facilities</p> <ul style="list-style-type: none"> -Experiences of residential care -On what grounds a decision was made about which aged care facility the person with dementia would live in | | <p>No details were specified about the residential aged care facilities</p> | <p>obtain rich descriptions of person-centred care</p> <p><u>Data analysis:</u> Qualitative content analysis</p> | <p>(e.g. personal things, pleasant environment)</p> <p>-Flexibility and continuity (e.g. flexible routines, available and present staff, staff consistency)</p> |
| <p><u>Author:</u> Ejaz, Noelker, Schur, Whitlatch & Looman</p> <p><u>Year of publication:</u> 2002</p> <p><u>Country of origin:</u> United States of America (USA)</p> <p><u>Quality checklist score:</u> 29/36</p> | <p><u>Aim:</u> To test a preliminary model to explain family satisfaction with nursing home care</p> <p><u>Research question:</u> How are family members' perceptions of the quality of care provided to their institutionalised relatives affected by:</p> <ul style="list-style-type: none"> -placement-related stress -their involvement in resident care and nursing home services - the type of care they think nursing assistants provide - family –staff interactions? <p><u>-Dependent variable:</u></p> <ul style="list-style-type: none"> -Family member's perceptions of quality of care assessed as a multidimensional construct comprising of 13 service/care areas and 2 staff areas using a Likert-scale assessing whether improvement was needed in each area <p><u>-Independent variables:</u></p> <ul style="list-style-type: none"> -Family adjustment to nursing home placement -Family involvement with | <p><u>Sample size:</u> N = 133</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Mean age = 61 (range 34-90)</p> <p><u>Gender:</u> Male = 30%, Female = 70%</p> <p><u>Ethnicity:</u> 84% Caucasian (other ethnicities not specified)</p> <p><u>Relationship to person with dementia:</u> 67% adult children (other relationships not specified)</p> | <p><u>Recruitment strategy:</u> Convenience sampling</p> <p>Each nursing home provided contact information for the primary family caregivers of residents with dementia. Families were sent a letter outlining the study and then researchers contacted them by telephone to screen them using the eligibility criteria</p> <p><u>Location:</u> Five suburban nursing facilities in the greater Cleveland area</p> <p>Two facilities were proprietary and three were non-profit. Four had special care units and they ranged in size from 82 to 203 beds</p> | <p><u>Data collection:</u> Cross-sectional survey design to conduct in-person structured interviews with family members</p> <p>The interview location was not specified</p> <p><u>Data analysis:</u> Two separate ordinary least squares multiple regression analyses were used to examine improvements needed in environment and administration, and direct care</p> | <p>More than 40% of relatives believed improvement was needed in:</p> <ul style="list-style-type: none"> -Manner in which complaints and concerns are handled -Amount of care received -Personalised attention -Care given by nursing assistants <p>Families perceived significant improvements were needed:</p> <p><u>1) in environment/admin when:</u></p> <ul style="list-style-type: none"> -They had negative interactions with other staff - The care by nursing assistants was not perceived to be sensitive - Family members gave more activities of daily living (ADL) help to their relative <p><u>2) in direct care when:</u></p> <ul style="list-style-type: none"> -They had negative interactions with other staff -Family members gave more ADL help to their relative |

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| | resident care -Type of care provided by nursing assistants -Family-staff interactions | | | | |
| <u>Author:</u> Hertzberg & Ekman <u>Year of publication:</u> 2000 <u>Country of origin:</u> Sweden <u>Quality checklist score:</u> 33/36 | <u>Aim:</u> To identify and describe obstacles to a well-functioning relationship between relatives and staff in order to suggest promoters of a well-functioning relationship <u>Research question:</u> Not explicitly specified <u>Topics covered:</u> Topics for discussion were not chosen by the researcher and the researcher did not act as a moderator during the discussions. Participants were encouraged to pursue topics which were of most concern to them. However, the group leaders occasionally directed them towards the task of the group: to discuss factors that could enhance understanding and relationships between staff and relatives. | <u>Sample size:</u> N = 10 <u>Participant details:</u> <u>Age:</u> Average age = 64 (range 40-80) <u>Gender:</u> Male = 2, Female = 8 <u>Ethnicity:</u> Not specified <u>Relationship to person with dementia:</u> Spouse = 5, Child = 3, Sibling = 1, Niece = 1, | <u>Recruitment strategy:</u> Participants applied for participation following an advertisement in the Dementia Association's local journal. Representatives of the Dementia Association (not the researcher) made the selection of participants <u>Location:</u> Not explicitly stated | <u>Data collection:</u> Non-participant observation of focus groups Three different groups (A, B and C) met six times, once every six weeks. Focus groups lasted 90 minutes Each group had a professional group leader and a representative of the Dementia Association who acted as a participant and as an assistant to the leader. Each group had three relatives and three staff members. The researcher acted as a silent non-participant in the discussions <u>Data analysis:</u> Sentence by sentence analysis inspired by the constant comparative method. Codes were generated based on the text and through constant comparison of these codes three categories emerged | Three main categories emerged: <i>-Influence and participation:</i> related to families' experiences of being asked questions and encouraged to participate by staff in the care of their relative. It also covered their experiences of activities for their relative with dementia. <i>-Uncertainty and distrust:</i> related to examples of families experiencing uncertainty and distrust in their relationships with staff <i>-Communication difficulties:</i> related to different aspects of communication between families and staff including information, conversations, opinions and questions. It also concerned the difficulties experienced by families in their interactions with staff members |
| <u>Author:</u> Legault & | <u>Aim:</u> To explain the transformation of the advocacy | <u>Sample size:</u> N = 14 | <u>Recruitment strategy:</u> Theoretical sampling | <u>Data collection:</u> Interviews lasting approximately 90 | Transformation of the advocacy role implicated three tightly interrelated |

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| <p>Ducharme</p> <p><u>Year of publication:</u> 2009</p> <p><u>Country of origin:</u> Canada</p> <p><u>Quality checklist score:</u> 35/36</p> | <p>role of daughter carers following the admission of an elderly parent with dementia to a long-term care facility</p> <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u></p> <ul style="list-style-type: none"> -Personal, relational and contextual conditions that influence transformation of the advocacy role -The actions and interactions that the advocacy role entails -The consequences of the advocacy role for participants and their institutionalised parents | <p><u>Participant details:</u></p> <p><u>Age:</u> Average age = 55 (range = 44-65)</p> <p><u>Gender:</u> Male = 0, Female = 14</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Child = 14</p> <p>Participants' relatives with dementia had been institutionalised for at least six months</p> | <p>(participants chosen based on their theoretical relevance to the stud rather than how representative they are of the population)</p> <p>A nurse contacted the possible participants and requested permission to forward their names to the researchers. The researcher then contacted them by telephone to explain the research and obtain consent</p> <p><u>Location:</u> Quebec, Canada</p> <p>Participants were recruited from three long-term care facilities (one specialised university geriatrics institute, two nursing homes). The facilities were located in a middle-class residential area and a less privileged neighbourhood</p> | <p>minutes in length conducted at the participant's home, the nursing home or the research centre</p> <p>An interview guide was developed but this evolved as a function of the results of the analysis, in line with a grounded theory approach. The initial interview guide contained five open-ended questions covering the general topics related to the phenomenon under study</p> <p><u>Data analysis:</u> Grounded theory</p> <p>Simultaneous data collection and analysis with the first interview immediately analysed and the results obtained used to determine the theoretical sampling and questions for further participants</p> | <p>intermediary processes:</p> <ul style="list-style-type: none"> -Development of trust in the care setting -Integration of the setting -Evaluation of quality of care <p><i>Developing trust in the facility and its staff</i> appeared to be at the core of the transformation of the advocacy role. Five factors were found to be associated with the establishment of trust:</p> <ol style="list-style-type: none"> 1)Quality of contact with staff on admission and information provided 2)Comparisons with other nursing homes 3)Staff demonstrating interest in clients 4)Staff responsiveness to family concerns 5)Transparency in the evident of accidents or incidents <p><i>Integration of the setting:</i></p> <ul style="list-style-type: none"> -Establishing a relationship of reciprocity with staff -Collaborating with staff -Diplomatic communication style <p><i>Evaluation of quality of care:</i></p> <ul style="list-style-type: none"> -Exercising judgment on quality of care -Weighting that judgment -Acting to change the situation |
| <p><u>Author:</u> Looman, Noelker, Schur, Whitlatch & Ejaz</p> <p><u>Year of publication:</u></p> | <p><u>Aim:</u> Not explicitly specified</p> <p>The study focuses on family members' positive perceptions of the care provided by nursing assistants</p> | <p><u>Sample size:</u> N = 113</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Average age = 60 (range = 34-90)</p> | <p><u>Recruitment strategy:</u> Not explicitly specified</p> <p><u>Location:</u> Cleveland, Ohio</p> <p>Participants were recruited</p> | <p><u>Data collection:</u> Structured in-person interviews</p> <p>The interview schedule was comprised of close-ended and open-ended questions</p> | <p>Four themes emerged:</p> <ul style="list-style-type: none"> -<i>Constraints on nursing assistants:</i> related to families' appreciation of the difficult role that nursing assistants have when working with clients with dementia |

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| <p>1997</p> <p><u>Country of origin:</u> United States of America (USA)</p> <p><u>Quality checklist score:</u> 26/36</p> | <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u> -Family members' positive perceptions of the care provided by nursing assistants -What had happened in the facility with regard to nursing assistants that had pleased family members the most ad bothered them the most -Areas of satisfaction or dissatisfaction with the nursing home</p> | <p><u>Gender:</u> Male = 40, Female = 93</p> <p><u>Ethnicity:</u> 83.5% Caucasian (other ethnicities not specified)</p> <p><u>Relationship to person with dementia:</u> Spouse = 24, Child = 89 (other relationships not specified)</p> | <p>from five skilled nursing facilities (four of which had special care units for memory impaired residents). The sites ranged in size from 82 to 203 beds. Three of the facilities were philanthropic and two were proprietary</p> | <p><u>Data analysis:</u> Content analysis</p> <p>All comments were reviewed to determine their basic substance and then four conceptual categories were identified and refined through systematic review of the interview schedules. Responses were content analysed and independently coded using the categories</p> | <p>-<i>Care exceeding expectations:</i> related to family members' reports of care provided by nursing assistants that had exceeded their expectations</p> <p>-<i>Nursing assistant expressiveness:</i> related to families' experiences of the positive physical and verbal expressions from nursing assistants towards their relatives</p> <p>-<i>Family-like relationships:</i> related to families' perceptions of the kin-like relationship that developed between nursing assistants and their relatives</p> |
| <p><u>Author:</u> MacDonald</p> <p><u>Year of publication:</u> 2006</p> <p><u>Country of origin:</u> Canada</p> <p><u>Quality checklist score:</u> 28/36</p> | <p><u>Aim:</u> To investigate which aspects of the institutional environment impacts leisure opportunities and choices of individuals with Alzheimer's disease in a long-term care facility from the perspectives of professionals and family caregivers</p> <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u> -How the environment impacts on leisure -Fun and enjoyable activities and why residents with Alzheimer's disease could not participate in these activities -Ways to enhance the quality of life of individuals with</p> | <p><u>Sample size:</u> N = 5</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Not specified</p> <p><u>Gender:</u> Not specified</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Both spouses and adult children of people with Alzheimer's disease participated, however the exact composition was not explicitly specified</p> | <p><u>Recruitment strategy:</u> Not explicitly specified</p> <p>Potential participants who met the eligibility criteria were contacted by the researcher</p> <p><u>Location:</u> Not explicitly specified</p> <p>Participants were recruited from a 120-bed long-term care facility which did not have a specialised care unit for people with Alzheimer's disease</p> | <p><u>Data collection:</u> Self-contained focus groups</p> <p>A semi-structured approach was used whereby interview guides contained broad questions that attempted to elicit relevant information from participants</p> <p><u>Data analysis:</u> Thematic analysis</p> <p>The focus group data was analysed by identifying recurring themes. The data was also analysed by an external individual and the researcher met with this person to compare the themes that had emerged</p> | <p>The following themes emerged:</p> <p>-<i>Lack of staff:</i> related to family members' concerns about the lack of staff and the consequences this had on their relatives</p> <p>-<i>Family involvement:</i> related to family members' feelings of guilt because they could no longer provide care to their family member</p> <p>-<i>Concerns for well-being of loved one:</i> related to family members' concerns about the day-to-day comfort of their relatives</p> <p>-<i>Physical environment:</i> related to family members' concerns about the physical environment in the facility</p> <p>-<i>Opportunity for leisure was limited:</i> related to family members' concerns</p> |

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| | Alzheimer's disease -What causes residents to become unhappy or uncomfortable in their daily lives | | | | about their relatives no longer participating in leisure activities |
| <u>Author:</u> Moyle et al <u>Year of publication:</u> 2014 <u>Country of origin:</u> Australia <u>Quality checklist score:</u> 30/36 | <u>Aim:</u> To explore family members' perceptions of what it means to value a person with dementia and how this might influence the quality of life of people with dementia <u>Research question:</u> Not explicitly specified <u>Topics covered:</u> -How family members and others valued their relative and how this influenced the quality of life of the person -The type of care provided -Their view of the role of caring for people with dementia -How people with dementia are valued by society -The impact of care provided by staff on the quality of life of the person with dementia | <u>Sample size:</u> N = 20 <u>Participant details:</u> <u>Age:</u> Not specified <u>Gender:</u> Male = 4 , Female = 15 (gender unclear for 1 participant) <u>Ethnicity:</u> Not specified <u>Relationship to person with dementia:</u> Spouse = 2, Child = 15, Grandchild = 1, Niece = 1, Friend = 1 | <u>Recruitment strategy:</u> Convenience sampling No further recruitment details were explicitly specified <u>Location:</u> New South Wales and Queensland, Australia Participants were recruited from four mixed-gender long term care facilities which were all owned by the industry aged care partner. All facilities provided low (assisted living), high (nursing home) and special (dementia-specific) care and they ranged in size from 50-125 beds | <u>Data collection:</u> Interviews Pragmatic, exploratory qualitative approach using a semi-structured interview schedule to engage family members in a discussion <u>Data analysis:</u> Assisted by a Leximancer computer-assisted concept-mapping programme to help identify key concepts or themes and their interrelationships. The concepts are rank-ordered in terms of their importance | Three main factors were found to be influencing the person with dementia being valued and their quality of life: <i>-The resident's room:</i> this related to the importance of the physical environment for the person with dementia <i>-The resident's day:</i> this related to family members' views regarding the importance of care staff taking time in their relative's day to spend time with them, provide activities and get to know them <i>-The resident:</i> this related to how the family member perceived and valued the person with dementia |
| <u>Author:</u> Mullin, Simpson & Froggatt <u>Year of publication:</u> 2011 <u>Country of origin:</u> | <u>Aim:</u> To focus on the lived experience of spouses of those with dementia in long-term care in order to aid understanding and help develop appropriate information and support for this group of people | <u>Sample size:</u> N = 10 <u>Participant details:</u> <u>Age:</u> Average Age = 73 (range = 54-89) <u>Gender:</u> Male = 6, Female = 4 | <u>Recruitment strategy:</u> Opportunistic sampling Participants were identified through information packs distributed via care home managers. They were asked to return a consent form after which they were | <u>Data collection:</u> Semi-structured interviews Interviews were conducted at either the participant's home or the nursing home and lasted between 50 minutes and 1 hour. An interview schedule was | Four themes emerged: <i>-Identity: 'till death us do part':</i> related to the identity of the participants in relation to the spousal relationship <i>-Making sense of change:</i> related to the changes family members experienced as their relative with dementia deteriorated |

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| <p>United Kingdom (UK)</p> <p><u>Quality checklist score:</u> 36/36</p> | <p><u>Research questions:</u></p> <ul style="list-style-type: none"> -What are the experiences of spouses/partners of individuals with dementia in care homes? -What meanings do the participants give to their experiences? <p><u>Topics covered:</u></p> <ul style="list-style-type: none"> -Experiences following placement of their relative -Support -The spousal relationship -Aspects relating to the care home -Thoughts about the future | <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Spouse = 9, Long-term partner = 1</p> | <p>contacted by the researcher</p> <p><u>Location:</u> North-West England</p> <p>Care homes were identified through the Commission for Social Care Inspection.</p> <p>Care homes recruited were within the private sector and had specific dementia care provision, a minimum quality rating of two stars and a minimum capacity of 20 beds</p> | <p>used as a guide with relevant prompts</p> <p><u>Data analysis:</u> Interpretative Phenomenological Analysis (IPA)</p> <p>Initial notes were written on the transcripts to create a list of possible subthemes which were then analysed to identify relationships between them and then rearranged or merged together as appropriate. This was repeated for each participant and compared to produce an overall set of themes</p> | <p><i>-Relationship with care provided: Visiting as surveillance:</i> related to family members' perceptions of care and the need for ongoing scrutiny with regards to the care provided</p> <p><i>-Relationship to the future: hope versus despair:</i> related to family members' feelings about the future</p> |
| <p><u>Author:</u> Palmer</p> <p><u>Year of publication:</u> 2012</p> <p><u>Country of origin:</u> United States of America (USA)</p> <p><u>Quality checklist score:</u> 28/36</p> | <p><u>Aim:</u> Not explicitly specified</p> <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u></p> <ul style="list-style-type: none"> -Experiences of caregivers who have placed their relative in a nursing home | <p><u>Sample size:</u> N = 15</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Average age = 56.7 years (adult daughters), 70.8 years (spouses)</p> <p><u>Gender:</u> Male = 4, Female = 11</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Spouse = 9, Child = 6</p> | <p><u>Recruitment strategy:</u> Not explicitly specified</p> <p><u>Location:</u> Not explicitly specified</p> | <p><u>Data collection:</u> Interviews</p> <p>Participants completed three interviews each scheduled 30 days apart. Each interview lasted 90 to 135 minutes and all took place in the family member's home except one held at the nursing home</p> <p><u>Data analysis:</u> Heideggerian hermeneutic (interpretative) phenomenology</p> | <p>Six themes related to communication emerged from the family members' narratives representing six desired patterns of communication represented by the acronym TALKKK:</p> <ul style="list-style-type: none"> -<i>Tell:</i> family members desired to be told information about their relative -<i>Ask:</i> family members desired to be asked to share their knowledge of their relative -<i>Listen:</i> family members wanted staff to listen to their concerns and knowledge -<i>Know:</i> families expected staff to get to know their relative -<i>Knowledge:</i> families expected staff to have specialist dementia knowledge |

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| | | | | | - <i>Knowledge to be shared:</i> families expected staff to share their specialist dementia knowledge with them |
| <p><u>Author:</u> Piechniczek-Buczek, Riordan & Volicer</p> <p><u>Year of publication:</u> 2007</p> <p><u>Country of origin:</u> United States of America (USA)</p> <p><u>Quality checklist score:</u> 27/36</p> | <p><u>Aim:</u> To explore factors involved in successful visitation for family members of people with dementia residing in a dementia special care unit</p> <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u> -Characteristics of a 'good' visit with a family member with dementia -Characteristics of an 'unsuccessful' visit -How the quality of visits can be improved</p> | <p><u>Sample size:</u> N = unclear (minimum 16, maximum 20)</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Not specified</p> <p><u>Gender:</u> Not specified</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Both spouses and adult children took part, however exact details were not explicitly specified</p> | <p><u>Recruitment strategy:</u> Not explicitly specified</p> <p>Staff members from the dementia special care unit identified family members who were willing to participate</p> <p><u>Location:</u> Not explicitly specified</p> <p>Participants were recruited from a 100-bed dementia special care unit in a Veteran's Administration Hospital</p> | <p><u>Data collection:</u> Focus groups</p> <p>2 focus groups were conducted with 8-10 family members participating in each session. Focus groups were facilitated by two of the authors</p> <p><u>Data analysis:</u> Grounded theory</p> <p>Transcripts were examined for emergent patterns and themes that reflected the meaning provided by participants in response to the main questions</p> | <p>Families identified numerous factors that affected their experience during visits to their relatives. These factors were grouped into three domains:</p> <p>-<i>Personal domain:</i> this included factors relating to the characteristics of the resident with dementia and their interaction with their relative</p> <p>-<i>Interpersonal domain:</i> this included factors relating to interactions between residents and staff and between family members and staff</p> <p>-<i>Environmental domain:</i> this included factors relating to the characteristics of the visiting space, the effect of other resident's presence and the availability of programs for the residents</p> |
| <p><u>Author:</u> Shields Scott</p> <p><u>Year of publication:</u> 1991</p> <p><u>Country of origin:</u> United States of America (USA)</p> <p><u>Quality checklist score:</u></p> | <p><u>Aim:</u> To identify what families expect from nursing staff caring for their relatives with dementia</p> <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u> Not explicitly specified</p> | <p><u>Sample size:</u> N = 26</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Not specified</p> <p><u>Gender:</u> Male = 10, Female = 16</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Spouse =</p> | <p><u>Recruitment strategy:</u> Not explicitly specified</p> <p><u>Location:</u> Not explicitly specified</p> | <p><u>Data collection:</u> Not explicitly specified</p> <p><u>Data analysis:</u> Not explicitly specified.</p> | <p>Both positive and negative accounts were provided in the following areas:</p> <p>-Appreciating families' experiences -Understanding families' feelings -Understanding patients' needs -Assuring patients' safety -Caring with skill -Helping families participate in care -Communicating with families</p> |

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| 7/36 | | 10, Child = 16 | | | |
| <u>Author:</u> van Zadelhoff, Verbeek, Widdershoven, van Rossum & Abma <u>Year of publication:</u> 2011 <u>Country of origin:</u> The Netherlands <u>Quality checklist score:</u> 36/36 | <u>Aim:</u> To investigate the experiences of residents with dementia, their family and nursing staff with group living for people with dementia <u>Research question:</u> Not explicitly specified <u>Topics covered:</u> -Expectations of group home living -Experiences of daily life and activities in the home -Contact and communication among residents, between staff and residents, and between family members and residents -Relations between family members and residents -Possibility to continue family habits and rituals -Possibility to hold on to former identity (personhood) | <u>Sample size:</u> N = 4 <u>Participant details:</u> <u>Age:</u> Not specified <u>Gender:</u> Not specified <u>Ethnicity:</u> Not specified <u>Relationship to person with dementia:</u> Not specified | <u>Recruitment strategy:</u> Not explicitly specified <u>Location:</u> Southern Netherlands Participants were recruited from two group living units located on the grounds of a traditional large-scale nursing home in an urban area. Each unit housed 10 residents with dementia who all required nursing level of care | <u>Data collection:</u> Participant observations and interviews Observations followed family members in different situations and held informal conversations with them In-depth interviews were conducted which began with an open question and lasted approximately 1 hour <u>Data analysis:</u> Not explicitly specified Transcripts were analysed by open coding focusing on recurring themes. Data were analysed by two researchers who discussed different themes and interpretations | Four important themes emerged for family members: - <i>Being part of:</i> related to how involved family members felt in the group life - <i>Taking responsibility:</i> related to how much responsibility family members took for their relatives - <i>Personalised attention:</i> related to the amount of time family members felt that staff had to spend time with their relative - <i>Well-being:</i> related to family members' perceptions regarding the well-being of their relative |

1.3.5.2 Aim

The studies reviewed here had different aims. Some focused more generally on family members' experiences of care provision (e.g. Mullin, Simpson & Froggatt, 2011), while others focused on specific aspects such as family members' relationships with staff (Duncan & Morgan, 1994) or the visiting experience (Piechniczek-Buczek, Riordan & Volicer, 2007). These differences may have influenced individual study findings because in studies with a particular focus some relevant staff factors may have been overlooked. Furthermore, the factors identified as contributing to families' satisfaction may be unique to those specific situations studied rather than their overall satisfaction with care provision.

1.3.5.3 Context

The majority of studies were conducted in North America; with three in Australia (Bramble, Moyle & McAllister, 2009; Edvardsson, Fetherstonhaugh & Nay, 2010; Moyle et al., 2014) and three in Europe (Hertzberg & Ekman, 2000; Mullin et al., 2011; van Zadelhoff, Verbeek, Widdershoven, van Rossum & Abma, 2011). Only one study was conducted in the UK (Mullin et al., 2011). Therefore, it is likely that there were differences in the funding arrangements, type of long-term care setting, staff makeup and style of care provision across studies from different countries. However, it was not possible to make distinctions between these due to a lack of contextual background information about the setting and style of care provided in most studies. Nevertheless, given the likely differences in care provision, the lack of contextual information limits the transferability of the findings.

1.3.5.4 Sample

Sample sizes were typically small across the studies reviewed. Ten studies had a sample size of 20 participants or less, with four larger studies incorporating up to 179 participants. In one study the number of participants was unclear (Piechniczek-Buczek et al., 2007). Several studies did not provide adequate participant demographic information, making it difficult to determine whether the sample was representative of the population. Furthermore, in studies which incorporated multiple relationships to the PwD (e.g. spouses, children, friends), no distinction was made between these in the results section.

1.3.5.5 Recruitment

The majority of studies used purposive or convenience sampling. However, four studies did not report this information (Looman, Noelker, Schur, Whitlatch & Ejaz, 1997; Palmer, 2012; Shields Scott, 1991; van Zadelhoff et al., 2011). One study incorporated theoretical sampling in line with the analysis method used (Legault & Ducharme, 2009). The recruitment methods employed limit the conclusions that can be drawn. A reliance on mainly purposive or convenience sampling methods across the studies reviewed increases the likelihood that some samples were not representative of the wider population and limits generalisability of findings and the inferences that can be drawn at population level.

1.3.5.6 Ethical Considerations

Over half of the reviewed studies made no reference to consideration of ethical issues. Whilst three studies did demonstrate this (Legault & Ducharme, 2009;

Mullin et al., 2011; van Zadelhoff et al., 2011); a further four studies only demonstrated partial consideration (Bramble et al., 2009; Edvardsson et al., 2010; Moyle et al., 2014; Piechniczek-Buczek et al., 2007). Given the nature of the topics researched, ethical issues such as informed consent and debriefing seem particularly important. It is unclear whether these studies did not consider ethical issues at all or whether their consideration was not reported.

1.3.5.7 Method

One study employed quantitative methodology (Ejaz, Noelker, Schur, Whitlatch & Looman, 2002) whilst the remaining 13 studies used qualitative methodologies. Studies did not always provide a clear rationale for their choice of methodology or indicate that alternatives had been considered. Whilst the majority of studies gave a clear description of the data collection process, other studies did not (Duncan & Morgan, 1994; Legault & Ducharme, 2009; MacDonald 2006; Piechniczek-Buszek et al., 2007; Shields Scott, 1991 & van Zadelhoff et al., 2011). Therefore it is unclear whether standard procedures were followed and it would not be possible to audit or replicate the data collection in those cases.

1.3.5.8 Method of Analysis

The majority of studies provided a clear description of the method of analysis employed (Bramble et al., 2009; Edvardsson et al., 2010; Ejaz et al., 2002; Hertzberg & Ekman, 2000; Looman et al., 1997; Moyle et al., 2014; Mullin et al., 2011 & Palmer, 2012); however, appropriate justification and theoretical rationale for this was often lacking. In addition, the majority of the qualitative studies did not specify

how many family members made reference to each topic or theme, making it unclear whether such topics were endorsed by the vast majority of family member participants or just a minority. Furthermore, only a few of the qualitative studies provided direct quotes from family members as supporting evidence for the themes reported. These omissions could highlight weaknesses in the analyses conducted, raising questions about the validity of study findings.

1.3.6 Analysis

Each study was read in full to identify its main characteristics. The results sections were summarised and compared to identify recurring staff factor themes. The identified themes were compared and clustered according to their overarching topic.

1.4 Results

The review findings are presented with regard to the main themes found across all the studies reviewed. The relevant staff factors thought to contribute to families' overall satisfaction with the ongoing care provided to their relative with dementia were divided into three major themes: family related factors, staffing related factors and client related factors. Each major theme was divided into several sub-themes which are presented and discussed in turn.

1.4.1 Family Related Factors

The way in which staff treated families was a central theme highlighted across twelve of the fourteen studies reviewed which seemed to contribute to families'

overall satisfaction with care provision. In particular, three sub-themes were considered important: the extent to which staff welcomed families, the relationship between staff and families, and the extent to which families felt appreciated or respected by staff. Each theme will be described and discussed in turn.

1.4.1.1 Welcoming Families

Being welcomed into the life and care of PwD was described as a central element to person-centred care (Edvardsson et al., 2010). Families expressed a desire to participate in their relative's care (Bramble et al., 2009; Legault & Ducharme, 2009) and appreciated staff encouraging them to share care responsibilities (van Zadelhoff et al., 2011). Families wanted to feel that staff actively encouraged them to maintain their relationship with their relative (Edvardsson et al., 2010). Furthermore, they wanted to be included in care planning and actively supported to participate in care (Shields Scott, 1991). Being asked their opinions or invited to participate in small tasks helped families feel welcomed (Hertzberg & Ekman, 2000). Indeed, families in one study noted the pleasant atmosphere in which they were treated as members of the home rather than visitors (van Zadelhoff et al., 2011).

Nevertheless, some families reported feeling that staff had not encouraged them to be involved in their relative's care (Bramble et al., 2009) whilst others felt at times that staff were communicating that they should not interfere (Hertzberg & Ekman, 2000). Furthermore, families stated they would appreciate an appointed time to talk about their relative's care but found this request was often ignored due to lack of time or a suitable environment (Hertzberg & Ekman, 2000). Whilst in general families wanted to be welcomed and encouraged to participate in care and made

negative comments when this did not occur; for some it seemed that this came with too much responsibility. For example, in one study families felt that being considered as more than just a visitor was too burdensome (van Zadelhoff et al., 2011).

1.4.1.2 Relationship between Families and Staff

Families expressed a desire to develop ongoing relationships with staff; an important part of which included staff sharing information and recognising their knowledge and experience as family members (Duncan & Morgan, 1994; Legault & Ducharme, 2009; Palmer, 2012). Indeed, the development of a relationship of reciprocity between staff and families was considered crucial as it helped families feel comfortable to ask questions, share knowledge and raise concerns or suggestions (Legault & Ducharme, 2009). Families indicated that the quality of their initial contact with staff and the information provided after admission was crucial for the staff-family relationship to take root and develop (Legault & Ducharme, 2009). Families reported feeling the need to establish relationships with staff in order to have some influence over them and to encourage high quality care (Duncan & Morgan, 1994).

Families also valued effective communication, highlighting its importance to their visiting experience (Piechniczek-Buczek et al., 2007). Indeed, good communication was identified as one of the positive care experiences that seemed to be related to families' satisfaction (Mullin et al., 2011). They reported finding it helpful when staff contacted them and made negative comments about communication if not informed of changes or problems (Shields Scott, 1991). Families described that

when staff actively communicated significant events rather than them having to seek out this information themselves this made them feel welcomed (Edvardsson et al., 2010). Indeed, families wanted staff to be forthcoming with information about their relative but did not always find this easy to obtain (Hertzberg & Ekman, 2000). Receiving conflicting reports resulted in families losing confidence in staff and poor communication led to feelings of anger and frustration, meaning they were unable to enjoy visiting their relative (Piechniczek-Buczek et al., 2007).

Furthermore, families wanted staff to share their specialist knowledge about how best to care for their relative (Palmer, 2012). However, some families reported being given inaccurate or insufficient information which they felt had led them to make the wrong decisions for themselves or their relatives (Hertzberg & Ekman, 2000). In one study families described a desire to build understanding with staff and wanted a more communicative relationship (Bramble et al., 2009). Although families expressed that working together with staff on practical tasks had improved their communication, they described such occurrences as rare (Hertzberg & Ekman, 2000).

1.4.1.3 Appreciating and Respecting Families

Families wanted staff to appreciate and respect their experience as family carers and to attempt to understand their feelings (Shields Scott, 1991). They appreciated staff attempts to validate their past experiences and provide reassurance (Duncan & Morgan, 1994) but did not appreciate staff giving negative opinions about choices they had made for their relative (Shields Scott, 1991). In some cases families mentioned that they would appreciate emotional support from staff (Shields Scott,

1991) or that they already felt supported by staff which exceeded their expectations (Looman et al., 1997).

Families wanted staff to listen and take them seriously when they asked questions, made a request or reported a concern (Legault & Ducharme, 2009; Palmer, 2012). How responsive staff were in these situations was taken as an indication of whether they took them seriously and families reported wanting concrete action to be taken rather than merely being appeased by staff (Legault & Ducharme, 2009). Families were concerned that if they criticised care no action would be taken or staff may give less attention to their relative (Hertzberg & Ekman, 2000). They gave several examples of situations in which the staff's reaction to their actions or questions left them feeling embarrassed or belittled (Hertzberg & Ekman, 2000). Indeed, more than 40% of families in one study believed that improvement was needed in how staff handled concerns or complaints (Ejaz et al., 2002).

Families wanted staff to take into account and value their extensive experience with the client (Duncan & Morgan, 1994) and wished to be given the chance to share their knowledge of their relative (Legault & Ducharme, 2009; Palmer, 2012). They expressed that staff taking their opinions seriously was of utmost importance as they wanted their narratives about their relative to be trusted and taken into account when providing care (Hertzberg & Ekman, 2000). Families wanted staff to take their suggestions on board and expressed frustration if staff appeared reluctant to implement their recommendations (Piechniczek-Buczek et al., 2007). However, some families reported that only a minority of staff demonstrated an interest in learning about their relative or took the initiative to actively seek life

history information (Hertzberg & Ekman, 2000). Furthermore, families expressed that those staff that sought this information did not pass this onto their colleagues (Hertzberg & Ekman, 2000).

Families wanted staff to recognise them by name (Duncan & Morgan, 1994) and take time to talk to them or share a cup of tea (Edvardsson et al., 2010; Hertzberg & Ekman, 2000). Some families reported having very little contact with staff which left them feeling as if their involvement in their relative's care was not being encouraged (Bramble et al., 2009). Families commented that staff not taking them into account made them feel neglected and as if they were not valuable (Hertzberg & Ekman, 2000). Furthermore, families reported negative interactions with staff, with some stating they were never contacted or only contacted in negative situations (Hertzberg & Ekman, 2000). Indeed, one study indicated that families who perceived significant improvements were needed in how staff cared for their relative had more negative interactions with staff (Ejaz et al., 2002).

1.4.2 Staffing Related Factors

A second major theme identified in thirteen of the fourteen studies reviewed related to families' staffing expectations. This theme was divided into three sub-themes representing the aspects of staffing that appeared to contribute to families' satisfaction: staff personality/attitude, staffing administration and staff trustworthiness. Each theme will be described and discussed in turn.

1.4.2.1 Staff Personality/Attitude

Staff personality and attitude was considered to be very important. For example, families valued the genuine warmth and caring that staff expressed to both themselves and their relatives (Looman et al., 1997) and wanted staff to relate to their relative in a professional and respectful manner (Duncan & Morgan, 1994). Families in one study described staff as kind, attentive, friendly and approachable and considered this to be a positive experience of the care contributing to their overall satisfaction (Mullin et al., 2011). In another study families highlighted the importance of staff demonstrating an attitude that conveys their interest in and familiarity with clients, and which shows them respect and kindness (Legault & Ducharme, 2009). Families in a further study seemed to value the staff approach which they described as “based on respect for personhood, with warmth, trust, openness, hospitality, care and honesty, both in contact with residents and family members” (van Zadelhoff et al., 2011, p.2495).

However, not all families reported positive staff attitudes or personality traits. For example, some spoke negatively about the inflexible attitude of some staff (MacDonald, 2006). Indeed, in another study, families reported that they felt significant improvements were needed when care provided by staff was not perceived to be sensitive (Ejaz et al., 2002). Some families attempted to monitor staff attitude towards their relative to ensure it was sensitive to their needs (Duncan & Morgan, 1994). Nevertheless, not all families felt that monitoring was needed, as in a further study families expressed their general satisfaction with staff attitude and friendliness (Bramble et al., 2009).

Families highlighted the importance of staff prioritising clients over the completion of tasks in order to demonstrate a person-centred approach (Edvardsson et al., 2010). Whilst this was considered crucial; some families even experienced staff prioritising clients in a manner that went above the call of duty. For example, staff would continue to care for their relatives during their breaks or work on their scheduled days off (Looman et al., 1997). It seemed that families felt that this demonstration of the staff's dedication was a sign of their interest in their relative and going beyond the usual boundaries of the staff-client relationship in this way exceeded their expectations (Looman et al., 1997). Whilst families did not expect this level of prioritisation it seemed that it was nevertheless admired and positively received.

1.4.2.2 Staffing Administration

Families highlighted the importance of adequate staffing levels, noting that this was particularly important for ensuring their relatives had ample opportunities for stimulation and attention to their particular needs (Piechniczek-Buczek et al., 2007). However, on occasion families felt the number of staff was inadequate (Mullin et al., 2011) and in some cases cited this as a reason why they felt the care provided was not sufficient (Hertzberg & Ekman, 2000). Furthermore, families highlighted concerns about the consequences insufficient staff had on clients such as being rushed and hurried leading to increased agitation (MacDonald, 2006). They also felt it contributed to their relatives receiving inadequate one-on-one time and reduced opportunities for staff to get to know their relative's past interests (MacDonald, 2006). Families felt there were too few staff to reassure them and wanted one staff

contact point but were mindful of the low staffing levels (Bramble et al., 2009). In a further study families demonstrated an understanding of the challenges understaffing presents, but nevertheless expressed negative opinions about the impact on staff's ability to provide adequate care (Looman et al., 1997).

Families described that in order to develop the trust and relationships with staff that are required for person-centred care, low staff turnover and consistency in staffing was needed (Edvardsson et al., 2010). However, they reported experiencing the lack of consistent staff as inadequate (Mullin et al., 2011) and made negative comments about high staff turnover and lack of consistent staff caring for their relatives (Looman et al., 1997). Furthermore, families reported that high staff turnover meant that some staff knew almost nothing about their relative (Hertzberg & Ekman, 2000). In addition, families reported feeling exhausted by having to start relationships with new staff on a regular basis (Hertzberg & Ekman, 2000).

Families also highlighted the importance of staff spending an adequate amount of time caring for their relatives. Indeed, families described that staff had to be available and present in order to be person-centred (Edvardsson et al., 2010). However, more than 40% of families in one study felt that improvements were needed in the amount of care staff provided (Ejaz et al., 2002). In another study families felt that management did not prioritise staff spending time with clients (Moyle et al., 2014) and therefore felt that improvements were needed in the amount of time staff spent interacting with their relatives. Furthermore, families described that person-centred care needed to incorporate flexible routines

specifically adapted to their relative's needs rather than around the needs of the organisation or staff (Edvardsson et al., 2010).

Families reported inexperienced staff as a concern that meant they felt the care provided was inadequate (Mullin et al., 2011). When family members in one study made negative comments about care provision they cited staff not being sufficiently educated as one of the reasons why the care was not sufficient (Hertzberg & Ekman, 2000). In another study families felt that staff had insufficient time for educational sessions but felt that sessions to improve their knowledge about dementia would improve the care they provided to clients (MacDonald, 2006). Indeed, families felt it was important that staff were knowledgeable about dementia in order to be able to care for their relatives and communicate with families regarding disease progression (Palmer, 2012).

1.4.2.3 Staff Trustworthiness

Families seemed to place great importance on their ability to trust staff to take care of their relative. They reported expecting the quality of care to be on par with the care they themselves would provide if their relative were at home (MacDonald, 2006). Families expressed that their perceived trust in staff was related to how much they felt they needed to monitor their relative's care. For example, families reported monitoring staff behaviour, paying particular attention to how their relative reacted to staff (Duncan & Morgan, 1994). Families suggested that if they did not monitor care provision then their relative may not receive appropriate care (Mullin et al., 2011).

A positive evaluation of care provision was associated with the development of trust; with a lack of trust resulting in families carrying out heightened supervision of staff (Legault & Ducharme, 2009). Indeed, families perceived that significant improvements were needed in care provision when they gave more help to their relative with ADLs (Ejaz et al., 2002). In a further study families reported their need for ongoing scrutiny of the care and would check their relatives were well cared for (Mullin et al., 2011). However, families in one study reported that they would expect staff to treat their relative well whilst they were visiting and so they would also monitor how staff treated other clients (Duncan & Morgan, 1994).

1.4.3 Client Related Factors

The third major theme identified in ten of the fourteen studies reviewed related to how families perceived staff related to their relatives. This theme was divided into two sub-themes representing the most important aspects that appeared to contribute to families' satisfaction: the relationship between staff and clients and how staff provided stimulation for their relatives. Each theme will be described and discussed in turn.

1.4.3.1 Relationship between Staff and Clients

The relationship staff developed with clients appeared to be a major factor contributing to families' satisfaction. Indeed, it was highlighted that despite other factors being important for families, "ultimately, it was the quality of the care that staff delivered to the resident that mattered most" (Duncan & Morgan, 1994, pp.240-241). In one study families identified kin-like relationships between their relatives and staff and stated that their relative was seen as a member of the staff's

family, something which they appreciated (Looman et al., 1997). Families indicated the importance of their relatives being treated as unique individuals who were more than just objects requiring care (Duncan & Morgan, 1994; Looman et al., 1997). Indeed, families stated that if staff treated their relatives as part of the workload rather than relating to them as a person then they would be willing to search for better quality care (Duncan & Morgan, 1994).

Families looked for emotional connections and relationships to develop between their relative and staff (Palmer, 2012) and viewed their connection as evidence that their relatives were being treated with care and respect (Piechniczek-Buczek et al., 2007). When families noticed staff demonstrating kindness and respect towards their relative and saw that they were on familiar terms it heightened their trust in staff (Legault & Ducharme, 2009). Indeed, families felt a sense of relief when over time their relative became attached to staff as they assumed this indicated that an appropriate level of care was being provided (Piechniczek-Buczek et al., 2007). In contrast, families in one study reported occasions in which their relative had been dressed in someone else's clothes and felt this may reflect the staff not connecting with their relative in a meaningful way (Bramble et al., 2009).

Families appreciated staff relating to their relatives as unique individuals with a specific history and individual qualities (van Zadelhoff et al., 2011; Looman et al., 1997). They described that person-centred care included staff supporting their relative to be the person they were before diagnosis and to continue with as normal life as possible (Edvardsson et al., 2010). Families expected staff to get to know their relative's needs, desires, routines and habits; reporting that respecting

the personhood of their relative was important (Palmer, 2012). Indeed, families described that staff awareness of their relative's history and their particularities was a fundamental part of person-centred care (Edvardsson et al., 2010).

Families wanted staff to relate to their relatives in a manner which reflected an understanding of their likes and dislikes, and also preserved their dignity (Looman et al., 1997; van Zadelhoff et al., 2011). Indeed, families did not want their relative's need for care to impact negatively on their personal dignity and worth (Duncan & Morgan, 1994). Furthermore, families stated that observing staff attending to their relative's needs for privacy and dignity was particularly reassuring (Piechniczek-Buczek et al., 2007). Families looked to see if staff recognised and were responsive to their relative's moods and behaviours (Palmer, 2012). It seemed that if families saw this it gave them the impression that the staff had developed a strong relationship with their relative.

1.4.3.2 Providing Stimulation for Clients

Providing meaningful activities was seen as an essential component of person-centred care (Edvardsson et al., 2010). Indeed, families highlighted the importance of staff providing opportunities and activities tailored to their relative's likes and preferences and felt that this indicated that staff valued the person (Mullin et al., 2014). Staff involving their relatives in meaningful activities adapted to their ability level in order to foster their self-esteem was also considered important (Edvardsson et al., 2010). Additionally, families wanted their relatives to have stimulation and opportunities for social engagement (Mullin et al., 2014; Piechniczek-Buczek et al., 2007) and highlighted the importance of staff encouraging and supporting their

relatives to participate in parties and celebrations (Edvardsson et al., 2010). Furthermore, allowing clients to do things they enjoy and to make their own decisions was considered important in person-centred care (Edvardsson et al., 2010). Indeed, families in one study reported that observing their relative's involvement in activities gave them a sense of relief and gratification (Piechniczek-Buczek et al., 2007).

Families reported mixed opinions regarding their experiences of activities for their relatives, with some reporting that they were a positive aspect of the care contributing to their satisfaction, and others reporting concerns about the lack of stimulation for their relative (Mullin et al., 2011). In a further study 43% of families reported that improvements were needed in the variety of activities that staff provided for their relatives and 48% felt improvements were needed in the amount of personalised attention that staff gave to their relative (Ejaz et al., 2002). Furthermore, families in another study were frustrated when there was a lack of client involvement in activities (Piechniczek-Buczek et al., 2007). Nevertheless, despite the differences in families' experiences, there was a general agreement that providing activities and stimulation was very important.

1.5 Discussion

The present literature review explored the relevant staff factors that appear to contribute towards families' satisfaction with the ongoing care provided to their relative with dementia in long-term care. The relevant staff factors which appeared to contribute to families' satisfaction fell into three broad areas: family-related factors, which focused predominantly on how staff interacted with families

themselves; staffing related factors, which focused on the organisation and composition of staffing at the long-term care setting; and client related factors, which focused on how staff interacted with families' relatives and the quality of care provided. The findings of the present review build on and extend findings from previous literature reviews which focussed more specifically on family experiences with care provision at certain points of transition (Hennings et al., 2010; Graneheim et al., 2014). In contrast, the findings presented here stem from research investigating the staff factors that contribute to families' overall satisfaction with ongoing care provision.

Although three themes arose across the studies reviewed some staff factors were only mentioned in one or a few of the papers reviewed. It appeared that, whilst there was broad consensus about the three main areas that seemed to contribute to families' overall satisfaction, there were differences in exactly how families wanted staff to respond to their relatives and themselves. It is possible that this may be accounted for by individual differences between family members who participated in the studies reviewed or it may be that these differences arose due to the different aims of each study and the particular questions that families were asked about their experiences.

1.5.1 Clinical Implications

Given that families' satisfaction with overall care was related to more than just the manner in which staff interacted with their relative, it is important that these additional staff factors are taken into account. For example, it appeared that the way in which staff interacted with families themselves and staffing related factors

also contributed to families' overall satisfaction. This has important implications for staff working with PwD in long-term care settings and also for managers of such facilities.

The findings indicate that managers or those persons in senior positions of responsibility in long-term care settings for PwD should consider several factors when planning their staffing. For example, families indicated concerns about the number and consistency of staff, staff knowledge, and staff attitude and flexibility both in relation to clients and families themselves. This has implications for how managers organise shifts and for staff training, recruitment and retention. Families wanted staff to be knowledgeable about dementia and to notice and be responsive to the needs of clients and also to their own needs as family members. This indicates that staff training in long-term care settings for PwD should focus not only on educating staff about dementia but also on the importance of establishing effective relationships with both clients and their families.

It has been recognised that when staff are appropriately educated, trained and supported this not only benefits PwD through higher quality care that promotes dignity and compassion, but also provides greater reward for staff leading to lower staff turnover and greater continuity of care (DOH, 2015). Therefore, improving staff training in light of the research evidence may not only contribute towards families' satisfaction with care directly in terms of the overall quality of care they observe, but it may also indirectly lead to greater consistency in staffing which appears to be another important factor contributing to their overall satisfaction. Furthermore, providing clinical supervision to allow staff to discuss their feelings

and experiences regarding their work may help to enhance their interactions and communication with clients and their families as it has been highlighted that it “can help ensure that people who use services and their carers receive high quality care at all times from staff who are able to manage the personal and emotional impact of their practice” (Care Quality Commission, 2013a, p.5).

Families wanted staff to recognise their relative’s value and relate to them in a way which recognises their individuality whilst respecting their dignity. Families also wanted staff to provide stimulation for their relative so that they could continue to participate in activities they enjoyed. The findings suggest that staff working with PwD in long-term care settings should be mindful not only of the relationships they develop with clients but also their ongoing relationships with families. Families wanted reciprocal relationships with staff in which they could ask questions, raise concerns and share their knowledge about their relative; whilst in return they expected staff to value their perspective by demonstrating an interest and seeking out this information as well as spontaneously offering support and information.

1.5.2 Limitations

Whilst studies written in different languages were found during the initial literature search for this review, only those written in English were included, which could have limited the overall findings. The present review included studies in which families’ relatives with dementia resided in a long-term care setting. However, the type of long-term care setting was not specified. Therefore, studies included in the present review included the perceptions of family members of PwD who resided in

a range of different long-term care settings. The lack of information regarding the type of long-term care settings limits the conclusions that can be drawn.

The studies included in the present review categorised family experiences as those from any close family member of PwD residing in long-term care irrespective of age, relationship to the person or gender. Therefore, it was not possible to consider similarities or differences between, for example, spouses and adult children of PwD residing in long-term care. However, it is nevertheless plausible that family members with different relationships to the person with dementia may have different experiences regarding the overall care of their relative and therefore different staff factors may contribute to their overall satisfaction with care provision.

In addition, the studies reviewed had a number of methodological weaknesses previously highlighted in the quality appraisal section, which limit the generalisability of the findings. It should also be noted that using a single quality appraisal checklist for both quantitative and qualitative studies could have resulted in some methodological weaknesses being missed. For example, the checklist employed did not consider the epistemological underpinnings of the qualitative studies despite this having been highlighted as important to feature within qualitative research methodology reporting (Spencer et al., 2003).

1.5.3 Future Research Directions

The present literature review has highlighted the limited amount of research focussing explicitly on families' overall perceptions of the ongoing care of their

relative with dementia in long-term care, and in particular the paucity of research explicitly focussing on relevant staff factors that contribute to families' overall satisfaction. Much of the literature reviewed here was drawn from articles focusing on specific aspects of the care provided to PwD residing in long-term care, such as families' perceptions of their relative's leisure opportunities or their relationships with staff. There is a need for further research focusing more explicitly on families' overall perceptions of the care provided to PwD in long-term care as well as a need for research that directly investigates staff factors that may contribute to families' overall satisfaction.

1.5.4 Summary and Conclusion

In light of a lack of clarity with regard to staff factors that may contribute to families' overall satisfaction with the ongoing care provided to their relatives with dementia in long-term care, the present review aimed to critically evaluate existing empirical literature in this area. The findings highlighted staff factors in three broad areas which appeared to contribute to families' satisfaction; family related factors, staffing related factors and client related factors. In terms of family related factors, families indicated that they wanted staff to welcome them into the life and care of their relative and wished for a reciprocal relationship with staff, with good communication and in which they were appreciated and respected. In relation to staffing related factors, families had particular expectations regarding staff attitude and personality. They wanted staff to prioritise their relatives over tasks and to be able to trust staff to provide high quality care. Furthermore, families wanted adequate staffing levels, consistent staffing and well-educated staff providing care.

These staffing issues were felt to directly impact on how staff related both to families and to PwD. With regard to client related factors, families wanted staff to establish a connection with their relative, to provide stimulation and engagement and to be responsive to their relative's individual needs.

These findings have important clinical implications for staff working with PwD in long-term care settings and for managers of these facilities. Further research focusing more explicitly on the staff factors that contribute to families' overall satisfaction with care provision is needed in order to corroborate and extend the findings presented here. However, given the importance of family satisfaction with the care of PwD, these findings provide insight into the main staff factors which may contribute towards this. Furthermore, these findings highlight areas for improvement which may ultimately improve the overall care of PwD in long-term care settings.

1.6 References

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Chapter 2: Empirical Paper

Experiences of healthcare assistants working with clients with dementia in residential care homes

In preparation for submission to *Dementia* (See appendix A for author instructions)

Overall chapter word count (excluding tables, figures and references): 7999

2.1 Abstract

The aim of the present study was to explore the experiences of healthcare assistants working with clients with dementia in residential care homes in the UK. Eight participants completed semi-structured interviews which were analysed by Interpretative Phenomenological Analysis. Data analysis revealed three main themes representing healthcare assistants' experiences: *the importance of relationships*, which referred to the importance of their relationships with clients, families and colleagues as well as their sense of attachment to clients; *something special about the role*, which referred to their perception that their role was unique and rewarding as well as their sense of commitment to the job; and *the other side of caring*, which referred to aspects of their role perceived as being more difficult, including dealing with emotions and conflicts within the caring role. Clinical implications stemming from these findings are discussed and future research directions indicated.

Keywords: Dementia, experiences, healthcare assistants, residential care homes

2.2 Introduction

2.2.1 Dementia Context

There are currently 800,000 people with dementia (PwD) in the United Kingdom (UK) and this figure is expected to rise to over 1 million by 2021 (Alzheimer's Society, 2012). In 2008-09, although the majority of PwD receiving social care services were community-based, 28% were in residential care and 14% were receiving nursing care (The Health Foundation, 2011). The proportion of PwD in Bupa care homes across the UK rose from 36% in 2003 to just below 44% in 2009 (Lievesley, Crosby & Bowman, 2011); while a more recent report estimated that "in excess of 80% of residents living in care homes have dementia or significant memory problems" (Alzheimer's Society, 2013b, p.v).

2.2.2 Quality of Dementia Care

Over recent years, improving the quality of care for PwD has gained priority in the UK healthcare agenda in light of reports highlighting the gap between the existing quality of care provision for PwD and high-quality care as indicated by research evidence (The Health Foundation, 2011). However, despite improvements in quality of care being advocated, a recent report by the Care Quality Commission (CQC) acknowledged that "the health and social care system is struggling to care adequately for people with dementia" (CQC, 2013, p. 1).

In 2013, the findings of a high profile public inquiry into serious failings at Mid Staffordshire NHS Foundation Trust were published. One of the recommendations outlined was the need for "an increased focus on a culture of compassion and

caring” (Francis, 2013, p.76). Although this enquiry did not focus specifically on the care of PwD, the authors acknowledged that “there are likely to be implications in the lessons and recommendations for other sectors which must be borne in mind” (Francis, 2013, p.17). Indeed, a Department of Health (DOH) document published this year outlined the government’s vision that all PwD should receive high quality, compassionate, person-centred care (DOH, 2015).

In order to provide such care, it has been highlighted that staff working with PwD must be well supported. For example, The Alzheimer’s Society published a position statement calling for this and specifically arguing that staff providing formal care must have sufficient training and support in order to provide good care (Alzheimer’s Society, 2013a). Furthermore, a DOH commissioned guidance document outlines principles for supporting PwD, including that “managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia” (DOH, 2011, p.2). However, despite highlighting the need for staff caring for PwD to be well-supported; neither document outlines what support should be offered. Arguably, only through understanding more about their experiences of working with PwD in care settings, can the support needs of formal carers of PwD be accurately determined.

2.2.3 Experiences of Staff Working with PwD

Staff working with PwD in care settings are recognised as having a “demanding job” (Edvardsson, Sandman, Nay & Karlsson, 2008, p.63) and can potentially be faced with a number of stressors including working with clients who may be uncooperative or unappreciative, dealing with families who require emotional

support, working with inexperienced colleagues and working in understaffed services (Zimmerman et al., 2005). Indeed, research indicates that the role can impact on staff psychological well-being. For example, Margallo-Lana et al. (2001) gathered questionnaire data on the emotional well-being of 225 staff caring for PwD in National Health Service (NHS) care facilities and private sector residential and nursing homes. They found that approximately 20% of professionals working with PwD were experiencing psychological distress and that care assistants were less likely than nurses to use positive coping strategies (Margallo-Lana et al., 2001).

Findings from other studies also indicate that care staff working with PwD can be negatively affected by their work. For example, an American study exploring the reactions of unlicensed staff working with PwD found that the majority of staff found the behavioural and psychological symptoms of dementia upsetting and/or bothersome (McKenzie, Teri, Pike, LaFazia & van Leynseele, 2012). In a similar vein, Edvardsson et al (2008) investigated predictors of job strain in a sample of nursing staff caring for older PwD. They found four significant predictors, including level of education, staff age, the perceived caring climate and opportunities for staff to discuss difficulties. They concluded that “preventing experiences of high job strain among staff may be of the utmost importance for managers in securing the well-being of their staff as well as securing the quality of care provided to residents” (Edvardsson et al., 2008, p.64).

Another study employing self-report questionnaires found moderate levels of burnout among staff working with PwD and highlighted that burnout “has been shown to have an impact on staff behaviour towards residents” (Duffy, Oyebode &

Allen, 2009, p.517). The study authors concluded that the emotional well-being of care staff, as well as the quality of care they provided to PwD, would be improved by improving the quality of their working lives (Duffy et al., 2009). Similarly, Brodaty, Draper and Low (2003) found that more than 30% of nursing home staff in their sample felt they had insufficient opportunity to discuss the psychological stress of their role, while more than 55% felt they did not know enough about dementia. Arguably, these findings further highlight the need for staff working with PwD to be well-trained and supported to improve their ability to carry out their role and ultimately improve quality of care for PwD.

2.2.4 Rationale for the Present Study

A significant minority of PwD live in long-term care settings and there has been a drive in recent years to improve the quality of such care provision (The Health Foundation, 2011). It is recognised that staff must be well trained and well supported in order to provide good care (Alzheimer's Society, 2013a), however, there is little guidance regarding the form this support or training should take and little evidence available from studies that have sought to understand the experience of such care staff. There is therefore a need to understand more about the experiences of staff working with PwD. It is possible that findings from research seeking to further understand their perspective and experience may serve to inform efforts to support them to provide high quality care to PwD.

Much of the existing literature focusing on staff working with PwD in care settings has employed quantitative methodologies. However, there is a need for research utilising qualitative methodology to further explore care staff experiences and

perspectives. Furthermore, in line with the research suggesting that less educated staff experience higher levels of strain (Edvardsson et al., 2008) and are less likely to use positive coping strategies (Margallo-Lana et al., 2001), the present study will focus on the experience of healthcare assistants without a nursing qualification. Finally, since a higher proportion of PwD live in residential care homes than in nursing homes, the present study will focus on the experience of staff working in residential care settings.

2.2.5 Aim

The aim of the present study was to explore the experiences of healthcare assistants working with PwD in residential care homes in the UK.

2.3 Method

2.3.1 Research Design

Due to the paucity of research addressing the experiences of healthcare assistants working with PwD in residential care homes a qualitative research design was utilised. Qualitative approaches focus on exploring, describing and interpreting the experiences of participants (Smith, 2008) so this research design was deemed appropriate due to the exploratory nature of the research and its focus on the actual experience of this staff group.

Interpretative Phenomenological Analysis (IPA) was selected as the method of analysis as this methodology offers a phenomenologically focused approach to the interpretation of detailed, reflective, first-person accounts from participants (Larkin & Thompson, 2012). Researchers using IPA firstly aim to try to understand and

describe their participants' world; and then to develop a more interpretative analysis in which they attempt to position their initial description in relation to the wider social, cultural and theoretical context (Larkin, Watts & Clifton, 2006). IPA recognises the role of the researcher within the analysis process; highlighting that they are engaged in a double hermeneutic because they are trying to make sense of the participant making sense of their experience (Smith, Flowers & Larkin, 2009).

2.3.2 Participants

Healthcare assistants or equivalent working with PwD were recruited from three local residential care homes providing 24-hour care for PwD; ranging in size from 24 to 43 beds. All residents had their own room with access to shared communal facilities and organised activities. In each home care staff possessed or were working towards nationally recognised care qualifications. Participants were assessed for eligibility using the inclusion and exclusion criteria outlined in table 2.1

Table 2.1 Participant Inclusion and Exclusion Criteria

| | | |
|--------------------|------|--|
| Inclusion Criteria | i) | Healthcare Assistant or equivalent |
| | ii) | Currently working with clients with dementia |
| | iii) | Currently working in a residential care home |
| | iv) | At least 18 years of age |
| Exclusion Criteria | i) | Non-English speaking |
| | ii) | Has a UK recognised nursing qualification |

Two participants were initially recruited for a pilot study and a further eight were later recruited for the main study. As IPA is primarily concerned with the detailed account of individual experience with a focus on quality rather than quantity; eight participants was considered an appropriate number in order to provide sufficient cases to enable the examination of similarity and difference, convergence and divergence (Smith et al., 2009). All participants in the present study were female and all described themselves as White British, with English as their first language. All had a minimum National Vocational Qualification (NVQ) Level 2 in Health and Social Care. Further relevant participant details are provided in Table 2.2.

Table 2.2 Participant Details

| Participant | Age | Length of Experience Caring for Clients with Dementia | Average Working Hours per Week |
|--------------------|---------------|--|---|
| P1 | 42 | 5 years 2 months | Not recorded |
| P2 | 56 | 17 years | 35 |
| P3 | 39 | 2 years | 19.5 |
| P4 | 49 | 9 years 1 month | 32.5 |
| P5 | 20 | 2 years 1 month | 28 |
| P6 | Not specified | 14 years | 32.5 |
| P7 | 20 | 1 year 11 months | 37 |
| P8 | 32 | 18 years 7 months | 36 |
| Average | 36 | 8 years 7 months | 31.5 |

2.3.3 Procedure

2.3.3.1 Ethical Procedures

Ethical approval was gained from Coventry University Ethics Committee (appendix D). The research was conducted with adherence to the British Psychological Society (BPS) Code of Ethics and Conduct (BPS, 2009) and Code of Human Research Ethics (BPS, 2010).

2.3.3.2 Pilot Study

A pilot study in the form of a focus group was conducted with two participants prior to the main data collection phase. For this, a semi structured interview schedule was designed to ask participants broad open questions about their experiences of working with PwD (appendix H). The focus group was audio-recorded, transcribed verbatim and the data were analysed using thematic analysis; a “method for identifying, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p.79). This method of data analysis was used to draw out broad themes (appendix I) which then informed the semi-structured interview schedule for the main study.

2.3.3.3 Materials

A semi-structured interview schedule for the main study (appendix N) was devised based on the themes identified in the pilot focus group, whilst considering the research aim, existing literature and in consultation with the supervision team. In line with recommendations for IPA methodology the questions were designed to be

open and expansive to encourage participants to talk at length with minimal input from the researcher (Smith et al., 2009). The questions aimed to elicit both positive and negative experiences of working with PwD as well as experiences regarding particular salient aspects of the work as identified through analysis of the pilot focus group data.

2.3.3.4 Recruitment

For the pilot focus group one local residential care home was sent a letter (appendix E) with the study details and focus group participant information sheet (appendix F). Approximately 1-2 weeks later when the manager was contacted they had identified two staff members who were interested in participating. The researcher contacted them to check their eligibility and to answer any questions. Both staff members met the inclusion criteria and consented to participate in the pilot focus group.

For the main study managers of five local residential care homes were sent a letter (appendix J) with study details and the participant information sheet (appendix K). Approximately 1-2 weeks later each manager was contacted to discuss the research and answer any questions. Following this, the participant information sheet and researcher's contact details were distributed to eligible staff by the care home managers. Eight staff who expressed an interest in participating were contacted to discuss the study and to check they met the inclusion criteria. All eight participants met the inclusion criteria and consented to participate.

2.3.3.5 Interview Procedure

Participants reviewed the participant information sheet once more and had the opportunity to ask any further questions. They then provided written consent to participate (appendices G and L) and completed a demographic information sheet (appendix M). Participants were interviewed alone by the lead researcher at their workplace between July and August 2014. Interviews were audio-recorded and lasted between 17 and 49 minutes (mean 35 minutes). Following the interview participants were reminded of their right to withdraw without giving a reason at any point up until a specific date and were given a copy of the participant information sheet to keep. The researcher de-briefed each participant, explaining the study aims and purpose and answering any questions. Participants were directed towards further sources of support should these be required.

2.3.4 Analysis

Following each interview the audio-recording was transcribed verbatim and then destroyed. Any potentially identifying information was removed and participants were given a participant code instead of their name. The data was analysed according to IPA methodology as outlined by Smith et al. (2009) (appendix O). An excerpt of a transcript with initial coding is provided (appendix P) along with emergent themes for one participant (appendix Q).

2.3.4.1 Validity of the Analysis

In accordance with guidelines outlined by Elliot, Fischer and Rennie (1999) for enhancing quality control in qualitative research several measures were used to

improve the overall validity of the analysis. Interview transcripts including the initial codings, emerging themes and final themes were reviewed by and discussed with the lead researcher's supervision team who are experienced in supervising research using IPA methodology. A single transcript was coded by a peer; following which similarities and differences between the codes and emerging themes were discussed and reflected upon to compare and contrast ideas relevant to the analysis. Where this produced divergent views the relevant transcript sections were reviewed and discussed at length until a consensus was reached. Furthermore, participant quotes illustrating each theme were carefully chosen to ensure they reflected the context of the transcript.

2.3.4.2 The Researcher's Position

The lead researcher was a Trainee Clinical Psychologist employed by a local NHS Trust. She had no prior involvement with the residential care homes involved in the study.

Prior to conducting the research the lead researcher anticipated that participants would have had limited training and opportunity for supervision and support in their role, perhaps because of her own experiences of working as a support worker in inpatient mental health settings.

2.4 Results

Data analysis revealed three superordinate themes and several subordinate themes, a summary of which is presented in table 2.3. Each superordinate theme is discussed narratively in turn with reference to the corresponding subordinate

themes and with consideration to points of thematic convergence and divergence.

Verbatim extracts from participants are used to illustrate each theme.

Table 2.3: Superordinate and Subordinate Themes

| Superordinate Themes | Subordinate Themes |
|---|----------------------------------|
| Theme 1: Importance of relationships | Knowing your client |
| | Sense of attachment |
| | Role of support from others |
| Theme 2: Something special about the role | Feeling important |
| | Rewarding role |
| | Commitment to the job |
| Theme 3: The other side of caring | Conflicts with usual caring role |
| | Dealing with emotions |
| | It makes you think |

2.4.1 Theme 1: The Importance of Relationships

Seven participants referred in various ways to the importance of relationships. For most this related to their relationship with clients but others also mentioned their relationships with families and colleagues as constituting a vital part of their role. It seemed that participants saw these relationships as crucial to enable them to provide appropriate individualised care but also viewed the development of close relationships as an inevitable consequence of providing such personal care.

2.4.1.1 Knowing your Client

Participants expressed the importance of getting to know clients and gaining an appreciation of their life history. The importance of being alert to individual needs rather than treating clients as a homogenous group was highlighted:

“I think just getting to know that person. I think if you treat each one as an individual and become part of their life” (P7, Lines 47-49).

There was a sense that this client knowledge helped participants understand how best to provide care for that person and increased their confidence in doing so:

“Obviously we know the people through the care plans and through their time here. So we know what we can do for distractions” (P8, Lines 51-53)

Furthermore, two participants suggested that they forget their clients have dementia:

“You just don’t think about the dementia” (P1, Line 298).

It seemed that, for these participants, part of their relationship with clients was based on treating them each as a person with individual needs rather than through a diagnostic lens. It could be argued that this *forgetting* of diagnostic labels helped them to connect with clients in a more human or person-centred way.

2.4.1.2 Sense of Attachment

Linking with the previous theme, three participants commented on the inevitability of forming a sense of attachment with clients:

“You can’t... you can’t not attach yourself to them. You can’t” (P1, Lines 226-227).

Indeed, three participants commented that they viewed clients as family members. This sense of attachment was not only viewed as inevitable but as important to the role:

“But in a way I think it makes me do my job better because I really care about them and I want the best for them” (P6, Lines 210-212).

It seemed that participants viewed the attachment as pivotal to providing the best care to clients but there was also an acknowledgment that attachment brings with it an experience of loss when a client dies:

“You wouldn’t be in your right mind if you didn’t get attached to them. But it’s hard letting them go. Like I said... It’s like losing a member of your own family” (P1, Lines 226-227).

However, this was not a universal experience. One participant stated that she did not feel a sense of loss when clients die, but rather she viewed client death in a

more matter-of-fact manner, as an inevitable part of life and something to be expected in this setting:

“It doesn’t bother me that much. It sounds really bad. But it’s part of... that’s an aspect of life isn’t it? I’m quite prepared for it. This is where I work. They’re all gonna go” (P3, Lines 217-220)

It seemed that because she did not feel the same sense of attachment to clients she was therefore less affected when they died. It could be argued that not establishing an attachment acted as a way of protecting her and made end of life care easier for her because she could take out the emotional element and focus on the practicalities. However, whilst this did seem to make it easier for her, it conflicts with the experiences of other participants who saw attachment to clients as essential to providing effective care.

2.4.1.3 Role of Support from Others

Seven participants expressed how well supported they felt in their role. This seemed to be related to the quality of their relationships with colleagues and managers, as they all described these as positive relationships in which they felt able to seek advice and support as necessary:

“It’s just like your colleagues. They’re always there for you. And your managers as well. They are always there for advice of what you should do” (P5, Lines 199-201)

Furthermore, the idea that participants felt well supported was further indicated by the fact that none mentioned seeking additional support from other sources.

Indeed, there was a sense that it was the shared experience between staff and their supportive relationships that negated the need for additional support:

“I have felt like the support from everybody here is enough for me” (P5, Lines 137-138).

Several participants commented on the importance of spending some time in a different physical space:

“But you just need a 10 minute break, a change of scenery. Deep breaths. Look at it from a different perspective after you’ve talked to somebody else” P7, Lines 302-305).

It appeared that this time out was facilitated by other staff and its usefulness was therefore dependent on participants’ supportive relationships with their colleagues.

Two participants also mentioned the importance of their relationships with families:

“I definitely like working with the families. It’s all part of it. You couldn’t do it without working with the families” (P7, Lines 73-74)

It appeared that for one participant in particular the relationships she established with families were seen as equally important as those she developed with clients themselves. It seemed that her relationships with families were built on the premise that an effective relationship can involve the sharing of knowledge and mutual support.

2.4.2 Theme 2: Something Special about the Role

All participants indicated in some way that they perceived there to be something special or unique about their role. For some this seemed to manifest itself in a sense of them feeling important and that their role was rewarding. Linked with this was an apparent commitment to their role and a sense that they could not imagine doing another vocation.

2.4.2.1 Feeling Important

Over half of the participants alluded to the idea that they perceived themselves to be an expert in their role. This seemed to be related to a perception of themselves and their expertise as being important in the overall care of PwD. For one participant in particular it appeared that she felt her knowledge and expertise was at times superior to that of other professionals:

“We have quite a few people as well I’ve noticed here that are in my opinion misdiagnosed. You know... a lot of GP’s and that will say “she’s got dementia” well not necessarily. There can be lots of other reasons” (P2, Lines 85-88).

It seemed that this participant believed that the nature of her role meant that she was in a better place to understand and diagnose dementia than other professionals who may see PwD in different contexts. However, this was only the view of one participant. All other participants who made reference to themselves as experts did so in a context that was appropriate to their role rather than relating to a task ordinarily conducted by other professionals.

Linked to the idea that participants saw themselves as experts was the idea alluded to by two participants that it takes a certain kind of person for the role:

“You have to have something somewhere. Whether it’s up here [gestures to head] or in your heart I don’t know... that makes you get on with people with dementia. It’s not the training. Don’t get me wrong the training helps. But you have to have something somewhere. I don’t know what it is. But this magic ingredient, not a lot of people seem to have it” (P2, Lines 265-269).

It appeared that she felt that only a special kind of person, possessing certain unspecified qualities, was right for the role. This therefore seemed to link to participants feeling important, as they saw themselves as being one of only a few people with the right skills and aptitude for the job.

For many participants, the idea that they were making a positive difference to their client’s lives seemed to contribute to a feeling that both they and their job were important:

“I like to think that we do make their lives a bit brighter” (P1, Line 385).

Furthermore, three participants mentioned receiving praise from families:

“Their family come in and say “oh P1 they look beautiful” or whatever, I love that. I love that bit of the job” (P1, Lines 109-110).

This praise appeared to give participants a sense of feeling valued and seemed to act as evidence that they were doing a good job and playing an important role in clients’ care. It could be argued that participants saw praise from families as

important because it is not always possible for clients to provide such feedback, particularly in the later stages of dementia. This would therefore highlight the importance of positive feedback from families in boosting participants and reinforcing the importance of their role.

2.4.2.2 Rewarding Role

Six participants referred to the idea that there is something particularly rewarding about their role. Their comments gave the impression that they felt privileged to work with PwD in this setting. Indeed, several participants stated that they could not imagine doing another role:

“Working with people with dementia is one of the best jobs that I think anyone could have. Obviously that’s just me personally... [laughs] but I just wouldn’t do anything else” (P5, Lines 289-291).

Furthermore, six participants commented that they felt privileged to be part of end of life care, indicating that they felt there was something special about caring for clients at this time:

“I know we care for them all the time, I know that. But it’s that final journey isn’t it?” (P1, Lines 199-200)

It seemed that participants gained satisfaction and reward from getting end of life care “right”. It appeared to be seen as an immensely important time during which they have a special role to carry out that was somehow more crucial to do “correctly” than other aspects of their clients’ care. It is possible that participants

felt a greater sense of responsibility for providing end of life care because there is only one chance to get it “right”.

“It’s just nice that we can at least carry out their wishes and it’s what they want and what the whole family want as well” (P4, Lines 444-445).

As this extract indicates, participants seemed to enjoy meeting the needs of both clients and their families and this appeared to be seen as a rewarding aspect of their role. However, it seemed that they may also feel a pressure to get it “right” and to make the experience of losing their relative easier for families; particularly when considering that the majority of families elect for end of life care to be provided by staff at the residential home as opposed to elsewhere.

Participants also saw other aspects of their role as rewarding. Over half described their experiences of gaining insight into their client’s past history:

“I find it a privilege to learn about people’s history. To go through people’s photographs. Because some people are quite private and they won’t always allow you to do that. But I find it quite a humbling experience and a privilege” (P4, Lines 649-652).

It appeared that participants felt honoured to be entrusted with such sensitive and private information. It seemed to further highlight the strength and depth of their relationships with clients and to contribute to participants’ sense that their role was rewarding and one of special status.

Seven participants made reference to enjoying noticing little things that clients say or do:

“Just simple things... you might see them pick up a paintbrush... or even just playing with a pack of cards. Whatever they’re doing with it it’s just moments like that that are quite nice” (P4, Lines 253-255).

It seemed that these experiences were a source of pleasure and that participants enjoyed witnessing these moments. Furthermore, participants also referred to feeling a sense of satisfaction when they themselves were able to make a positive difference:

“If I can make one person smile in a day then I know I’ve done my job properly. And that’s what it’s all about for me” (P1, Lines 377-378).

As this extract indicates, it seemed that participants felt a strong sense of both appreciation and satisfaction when they made a positive difference and that they perceived this to be a valued part of their role. It appeared to be linked to the idea that their role was a privileged and rewarding one whereby they not only witnessed special moments in their clients’ lives but also played a part in contributing towards these.

2.4.2.3 Commitment to the Job

Participants consistently indicated that they felt the positives of their role outweighed its negatives. It seemed they wanted to give a positive impression of the role and that therefore any negative experiences were played down or not afforded as much importance as more positive experiences:

“I don’t think there’s much negative. I think it’s a lot of positive. I think it gives a lot of positive feelings. I can’t... I couldn’t think of anything really... I can’t think of anything really negative” (P4, Lines 576-578).

This wish to portray their role in a positive light appeared to indicate a sense of pride whereby they wanted it to be perceived positively by others and so felt it was their responsibility to help shape such perceptions. Furthermore, although participants acknowledged experiencing negative emotions relating to their role, they tended to brush these feelings aside and there was a sense that positive feelings associated with the role carried more weight:

“The positive feelings outshine the negative ones that you get” (P5, Lines 252-253).

As this extract highlights, it seemed that participants felt such a sense of pride and commitment to their role that they were happy to withstand any negative feelings. Additionally, two participants indicated that their commitment to their job goes beyond the call of duty:

“We’re supposed to start at half past 7 so I come in about ten past 7, put the porridge on” (P1, Lines 30-31).

Another participant reported taking clients to the park whilst on their break. These participants seemed to take their caring responsibilities so seriously that they continued to care for clients even in their free time. This seems to link to the sense of attachment participants felt to their clients, in that, even when they were not working, they still felt a sense of responsibility towards them. Going the extra mile

in this way appeared to indicate participants' sense of pride in their role and commitment to the clients.

In contrast, participants also alluded to a sense of 'forced' commitment in that they felt expected to stand in during staff absence:

"If somebody doesn't turn up on that shift then you know you really do have to stand in on that shift if nobody else will" (P1, Lines 149-150).

It seemed that participants felt they had no option but to remain on shift during colleague absence despite their tiredness or responsibilities outside work.

"Even when you're not on shift you might end up coming in for any reason" (P8, Lines 30-31).

It appeared that this participant felt a keen sense of responsibility even when she was at home as there was always the possibility she could be called to work. These extracts highlight the different experiences among participants and indicate that whilst for some their sense of commitment was portrayed as a choice and seen positively, for others this was not the case and instead it was seen as imposed upon them.

Two participants made reference to their anger about how others treat clients and their passion for advocating for them:

"I still don't feel that people with dementia are treated equally in a lot of aspects. Because I've yet to meet someone with dementia who can't make some kind of decision. You know... even a basic... you know what to eat. They can all do it to an

extent. Some more than others. And they're not always given that chance. That I don't like" (P2, Lines 247-251).

It seemed that for these participants wanting to advocate for clients linked with their sense of commitment to them and to their supportive role. It appeared that they felt a sense of responsibility to do this and saw it as an important part of their role.

2.4.3 Theme 3: The Other Side of Caring

In contrast to the previous themes which focused more on participant's positive experiences, another theme emerged which related to the more difficult aspects of their role. Participants either alluded to or spoke explicitly about the challenges they face and the impact of these on their thought processes and the emotions they experience as a consequence of the role.

2.4.3.1 Conflicts with Usual Caring Role

Four participants talked about being unable to make everything better for their clients:

"You're just trying to make them comfortable. But if they're not comfortable then that's when it's a bit heart-breaking. But then... you just try to do whatever you can..." (P5, Lines 188-191).

It seemed participants experienced great frustration and discomfort when unable to make their clients comfortable, despite how much they wanted to be able to do this. It appeared that being unable to support clients in the way they wanted could

result in a conflict; apparently challenging their sense of their role or their role identity, which appeared to include an element of being able to make a positive difference to clients' lives.

Related to this, two participants stated they had found themselves wondering whether they could have done anything more for their client:

"The only thing that sort of gets to me at times is if... if probably somebody's unwell. I sort of think to myself you know "am I... am I doing enough?" or "should I have done this?" Erm... and sometimes I'll question myself. You know "am I doing the right things here?"'" (P4, Lines 625-630).

It is possible that because of their supportive role, being unable to help a client meant that they assumed they had not fulfilled their role adequately rather than that there was simply nothing else they could do. Therefore, this indicated that participants were experiencing a conflict in comparison to their usual caring role.

Three participants spoke about how difficult they found witnessing deterioration in their clients:

"And just the deterioration...Just seeing them go... every day just a little bit" (P6, Lines 157-158)

It seemed they found it upsetting to witness deterioration and in particular to observe changes in clients they know well. It appeared this was related to their sense of attachment to clients and also represented a frustration that they could not prevent the deterioration or alter its course. Therefore, this also seemed to be

indicative of a conflict between their usual role to provide care and support and to help clients feel better, and a situation in which they were unable to do this.

Furthermore, participants expressed their frustration when administrative tasks took priority over direct client care:

“I wish I could spend my whole day with them. But unfortunately I can’t because of paperwork and horrible things like that” (P2, Lines 208-209).

It seemed that this created a conflict for participants with respect to their usual caring role because administrative tasks were generally regarded as less important than spending time with clients. It appeared that it was hard to strike a balance between time spent on such tasks and time spent directly with clients. These participants implied that they felt direct client contact should take priority over administrative duties.

2.4.3.2 Dealing with Emotions

Participants described their role as both physically and emotionally draining, and reported experiencing a range of different emotions:

“You get so many emotions. So many. It’s... half the time you probably don’t even notice them because it just sometimes can be continuous. You know swapping from one to another and...” (P2, Lines 389-391).

For this participant in particular it seemed that she was so used to experiencing different emotions and the speed with which they change that coping had become second nature:

“Probably because I’ve been doing it so many years... erm... perhaps I don’t know you don’t get immune to it but you just cope without realising that you’re coping I think” (P2, Lines 415-418).

She seemed to acknowledge that her length of experience had possibly made it easier to deal with the emotional impact of the work. Indeed, two other participants made reference to their experience helping to make the work easier to cope with, particularly in relation to coping with end of life care:

“It was every time that I was on shift and... so I had to deal with it and I think that’s why I got so used to palliative care” (P1, Lines 241-242)

However, other participants seemed to need to seek reassurance from others or to reassure themselves to help cope with the challenges of the role:

“You get that sort of positive bit of feedback so that a lot of the time it does actually make you feel better. You think “actually yea... it’s not that bad. I don’t need to be worrying”” (P4, Lines 738-740).

It appeared that participants found comfort in receiving positive feedback and reassurance from others. However, half made reference to the idea that their emotions are not valid and they implied that they felt that they should just carry on:

“Now we’re seeing... residents where they can be very rude. Very very nasty. But like I said that is just part of their condition. You don’t take it personally. You... you do deal with it” (P4, Lines 392-394).

It was apparent that those participants who made reference to this idea believed that because their role is to support PwD, they just had to deal with clients' behaviour and how they made them feel. It seemed that participants felt that these feelings were to be expected and that therefore somehow they were not valid or worthy of attention. Their comments gave the overall impression that whilst their clients needed to be supported with their difficult emotions, they themselves did not have the same right.

2.4.3.3 It Makes You Think

Three participants commented that working with PwD had challenged their preconceptions about older people and PwD:

"I used to have the impression that old people are a bit... stuck in the mud. You have to be careful what you say" (P4, Lines 667-670).

Their accounts indicated that their perceptions of older people and PwD had changed in a positive way since working in this setting. However, it appeared that for some participants it was difficult and upsetting to try to put themselves in their clients' shoes and understand what having dementia is like:

"You just think "how could you just forget that if you do it every day?" (P5, Lines 230-231).

Nevertheless, two participants indicated that they felt that PwD cannot be truly happy or that they somehow have a worse quality of life than other people:

"Hopefully they can lead... well it is a normal life... as possible" (P4, Lines 170-171).

Furthermore, there seemed to be a sense for two participants that they did not want to be a client in the future:

“I don’t particularly want to end up that way” (P3, Lines 267-268).

It appeared that although they did not want to envisage the prospect of having dementia, their role nevertheless made them consider this possibility. Indeed, two participants expressed that the role made them draw parallels with their own life:

“Scary. When you think about what’s ahead [laughs] and you think “I wonder whether I’ll ever end up like that. I wonder what my family would be like, my children, if I was like that?” It makes you think. (P7, Lines 224-226).

Overall, it was clear that their experiences gave a new meaning to what one might expect from later life and meant that participants had to confront the future possibility of dementia whether or not they wanted to do this.

2.5 Discussion

The present study explored the experiences of healthcare assistants working with PwD in residential care homes. Data analysis revealed three superordinate themes, each of which are discussed in turn below, before consideration of the clinical implications, study limitations and directions for future research.

2.5.1 Discussion of Study Findings

The first theme ‘importance of relationships’ refers to the perceived importance of participants’ relationships and sense of attachment to clients, as well as their relationships with colleagues and families. Getting to know clients and forming

relationships with families was considered extremely important, consistent with previous research in which staff working with PwD have described such relationships as essential to the provision of person-centred care (Edvardsson, Fetherstonhaugh & Nay, 2010). Participants generally viewed their sense of attachment to clients as being both inevitable and important for quality care but nevertheless acknowledged the emotional difficulty this caused when clients died. However, one participant did not feel the same sense of attachment, highlighting differences in how participants related to PwD. It is possible that not forming an attachment to clients may have acted as a protective mechanism for this participant. Interestingly, it has been suggested elsewhere in the literature that such detachment or emotional distancing from clients by healthcare professionals can actually help them carry out their role (Oakley & Cocking, 2004). Furthermore, participants described relationships with colleagues as being an important source of support. This is consistent with findings from previous research conducted in inpatient settings, which indicated that the relationships formed between staff working with PwD acted as an important coping mechanism (Schneider, Scales, Bailey & Lloyd, 2011).

The second theme 'something special about the role' referred to the rewarding aspects of participants' role such as making a difference, feeling important and their sense of commitment to the job. Overall, participants gave very positive accounts of their experiences and tended to play down the negative aspects of their work. This observation is also consistent with findings from previous research which found that healthcare assistants working with PwD in inpatient settings used

a psychological strategy they termed 'desensitisation' to tune out negative stimuli whilst focusing on the rewarding aspects of the role to enable them to work effectively (Schneider et al., 2011, p.44). Participants in the present study appeared to gain a sense of pride and enjoyment from their work and gave the impression that their role was both rewarding and satisfying. Furthermore, participants sense of commitment to their role and inability to imagine doing another vocation seemed to further reflect their satisfaction. These findings are consistent with previous research indicating that staff working with PwD report good levels of job satisfaction (e.g. Moyle, Murfield, Griffiths & Venturato, 2011).

The third superordinate theme, 'the other side of caring', referred to the more difficult aspects of participants' role including not being able to make everything better, dealing with difficult emotions and facing the reality of dementia. It seemed that these challenging aspects of their role led participants to experience a variety of emotions. However, generally, they indicated that their emotional responses were not important to address and stated that their experiences were to be expected as part of the job role. Indeed, participants did not make reference to seeking specific support to help them cope with the emotional impact of the work. This finding is difficult to account for and may be partly explained by descriptions from some participants of the supportive nature of peer relationships at times of difficulty. It may also simply reflect participants' expectations of their role, as suggested above, however; it is noteworthy that research elsewhere found that care assistants were less likely than nurses to use positive coping strategies (Margallo-Lana et al., 2001).

2.5.2 Clinical Implications

The findings of the present study highlighted that participants not only valued their relationships with clients, families and colleagues but saw them as essential to care provision. This suggests that residential care home managers should encourage care staff to build strong and supportive relationships within their role. However, managers must also recognise that staff may become attached to clients and therefore find the emotional impact of their loss or death difficult to cope with, highlighting a need to ensure that staff have access to adequate sources of support if required.

Furthermore, participants indicated a tendency to disregard their own feelings and in particular any difficult emotions they experienced. Nonetheless, it is important that staff have opportunities to discuss and process their emotions to reduce any adverse impact on the care they provide. There are several ways in which this might be facilitated, for example through reflective practice groups or clinical supervision. Furthermore, managers and those in positions of responsibility within care homes could model the importance of acknowledging feelings and support staff to do this by embedding it into training and practice.

2.5.3 Study Limitations

Participants in the present study were all White British females whose first language was English. Although the majority of staff working in UK residential care homes are female (Eborall, Fenton & Woodrow, 2010); there is also “a rich nationality and ethnic mix among care home staff, with a high proportion speaking

English as an acquired language” (Luff, Ferrerira & Meyer, 2011, p.4). Therefore, this indicates that the sample was not representative of the general staff population in such settings. Furthermore, in light of the methodology employed the sample size was small. These sample characteristics limit the transferability of the findings. Furthermore, opt-in participation for care home managers and staff could have biased the results towards staff who were more enthusiastic about their role or had more positive experiences.

In addition, the research questions were devised following a pilot study with two staff members. However, other staff members may have answered differently, meaning that the resulting questions in the main study could have been different. Therefore the responses of these participants may have influenced the data set and ultimately the themes derived from the research. Furthermore, the researcher’s position as a Trainee Clinical Psychologist may have influenced participants’ responses. For example, they may have been more inclined to provide a psychological take on their experiences.

2.5.4 Future Research Directions

The present study highlighted the paucity of qualitative research exploring the experiences of staff working with PwD in residential care homes. Future research could usefully build on these findings by exploring the experiences of qualified nursing staff working with PwD in residential care settings. It is possible that their experiences would be different given the differences in their role and responsibilities as well as the differences in their training and educational background. Furthermore, it would also be interesting to explore and compare the

experiences of staff working with PwD in nursing homes and in NHS inpatient settings.

In addition, as the present study focussed broadly on healthcare assistants' experiences of working with PwD, future research could extend the focus to more specific aspects of their experience. For example, the theme 'the other side of caring' could be further investigated to gain clarity on the specific aspects of their role that healthcare assistants find more difficult. As previously highlighted, staff working with PwD in such settings may benefit from clinical supervision or training to help them understand and process their emotional responses to the work. Therefore, further research exploring the impact of *difficult* experiences may be beneficial in helping to provide clearer recommendations for staff support.

2.5.5 Summary and Conclusion

The present study employed semi-structured interviews to explore the experiences of eight female healthcare assistants working with PwD in residential care homes in the UK. Data analysis using IPA revealed three main themes: *the importance of relationships*, which incorporated their relationships with clients, families and colleagues as well as their sense of attachment to clients; *something special about the role*, which referred to their perception that their role was unique and rewarding, as well as their sense of commitment to the job; and *the other side of caring*, which referred to the more difficult aspects of their role including dealing with emotions and conflicts with the caring role. The findings have important clinical implications, particularly regarding the use of clinical supervision and training to help support such staff and in providing a high quality of care to PwD.

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Chapter 3: Reflective Paper

Personal reflections on working with people with dementia

This paper has not been prepared for submission to a journal

Overall chapter word count (excluding references): 4000

3.1 Introduction

This paper incorporates my own reflections on working with people with dementia (PwD), including my experiences of working with their families and the staff involved in their care. Given that my empirical and literature review papers focus on the experiences of staff and the perceptions of family members whose relatives with dementia reside in long-term care, it seemed pertinent to consider and reflect upon my own experiences of working with PwD. My perspectives regarding working with PwD have changed considerably as I have gained more experience and knowledge over time and completed doctoral training in clinical psychology. In this paper I draw on my perceptions and experiences during this journey and think about how they have led me to question my previous anxieties about working with this group of people. Finally, I explore the impact that this journey has had on my outlook as I move towards qualifying as a clinical psychologist.

3.2 Experiences Prior to Training

3.2.1 Voluntary Work

My first experience of interacting with PwD was at the age of 16 when I worked as a hospital library volunteer taking library books to patients on the wards. In this role I came across many PwD who I noticed often seemed confused and distressed. Some would cry out “where am I?” to anyone around them, including myself. I remember feeling very uncomfortable and not knowing how to respond. My instinct was to turn away rather than engage with the person because I did not know what to say for the best. No-one had taught me or demonstrated how to interact with PwD.

Without any guidance to follow, I floundered and looked to the ward staff for inspiration. I can recall staff telling me not to bother speaking to the PwD as “they have dementia so they won’t be able to read a book”. At the time, knowing almost nothing about dementia, I accepted this without question or real thought about whether the statement was accurate. Although my discomfort did not completely ease, being given direction made me feel that ignoring the PwD was justified and the best thing to do in this situation.

Thinking about this now makes me feel very uncomfortable. I am not surprised by my own reaction at the time as I can understand what led me to respond in the way I did. Turning a blind eye in this way seemed to act as a defence mechanism to protect myself from the uncomfortable situation. However, with the benefit of hindsight and more knowledge and experience I feel embarrassed and appalled that I ignored the PwD as I did. I am also shocked at the attitude of the ward staff in denying the PwD the same opportunities as patients who did not have dementia. It has made me wonder whether this attitude is common today or whether it was unique to the particular culture within the hospital I worked at the time. However, it appears that such an attitude is still common, as a report published relatively recently acknowledged that “there is a widespread assumption that people with dementia cannot take part in ordinary activities” (Alzheimer’s Disease International, 2012, p.73).

I feel sad that I did not know and that no-one taught me to treat PwD as just that; people. But at the same time, I also feel upset and disappointed that I needed to be taught this, rather than it being instinctive and natural to treat PwD with the same

respect and humanity as I would treat other people. It has made me think more broadly about why this response was not instinctive for me and whether my response mirrors that of other people who come into contact with PwD for the first time. A report published earlier this year outlined the prime minister's vision of "a society where the public thinks and feels differently about dementia, where there is less fear, stigma and discrimination; and more understanding" (Department of Health (DOH), 2015, p. 6). This indicates that negative attitudes and behaviours towards PwD do currently exist within the general population.

Furthermore, given that guidelines are available regarding how to communicate with PwD (e.g. Care UK, 2014); it appears that not knowing how to communicate effectively with PwD may be a relatively common experience. Whilst I agree that such guidelines may be both useful and necessary, it nevertheless leaves me saddened to think that whilst PwD may be struggling to come to terms with their diagnosis the very people they might look towards for support may need guidance about how to interact with them. I wonder whether such guidelines, which at first glance appear to be a positive step forward for helping to ensure that PwD are treated with the kindness and respect they deserve, may actually serve to make them feel less respected than prior to their diagnosis. This has highlighted the importance of paying careful consideration to the direct and indirect messages that we as professionals give about PwD, particularly considering that people who have never come into contact with PwD before may look towards us for inspiration and guidance, just as I did on the hospital wards.

3.2.2 People with Learning Disabilities

My first Assistant Psychologist position was in a Community Learning Disability Team where I was involved in conducting dementia screening assessments for people with learning disabilities (PwLD). The professionals with whom I worked demonstrated a different attitude towards working with PwD than I had experienced as a hospital volunteer. They interacted with PwLD who had a diagnosis of dementia in a way that I now understand as in line with the concept of personhood, that is, “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood, 1997, p. 8). This experience made me think about dementia in a different light and made me feel that interacting with PwD was not such a scary prospect as it had once seemed. This highlighted to me the importance of educating people who come into contact with PwD about the importance of treating the person with the same kindness and respect you would accord a person without a dementia diagnosis.

This post was my first experience of considering dementia in a psychological setting and a learning point for me as I had not previously considered the possibility of PwLD having a dementia diagnosis. I wonder whether this was in part due to the portrayal of PwD in the media as at the time; I had only ever seen images or articles about older PwD and no references to PwLD who had dementia. Although I have since seen more articles about PwLD who have a diagnosis of dementia, I wonder whether this is due to having actively looked for them as part of my clinical work as opposed to them being more prominent in the media.

Indeed, even recently it was highlighted that “there is little acknowledgement in policy that not everyone with dementia is an older person, nor that before a diagnosis of dementia an individual may already be living with reduced cognitive abilities and different communication strategies” (Watchman, 2014, p.32). Given that policies serve to inform the general public, this further highlights the importance of the messages that professionals and policymakers portray to the general public and the media regarding PwD. It seems to underscore the responsibility we have when working with PwD to ensure that we not only model interaction that is not filtered through a diagnostic lens, but also that we give accurate and well-informed messages about dementia.

3.2.3 Summary

Prior to training I had not come across PwD in my personal life. I think this contributed to my uncertainty and fear about interacting with PwD in my voluntary work. Although my Assistant Psychologist position was a more positive experience, I was nevertheless aware that my knowledge and experiences of working with PwD were still relatively limited. This made me feel worried about working with PwD and their families during clinical training. In particular, as I learned more about dementia and the progression of the disease I became concerned about how helpless I would feel if I had to give a dementia diagnosis, which I had come to understand as a terminal one in which the person gradually loses their cognitive and functional abilities. I also wondered whether working with PwD would make me draw parallels with my own life and think about the possibility of myself or a

family member receiving a dementia diagnosis and how upsetting this prospect might be.

I spoke about these fears in my doctorate interview when asked whether there was a client group with whom I might find it difficult to work. I acknowledged worrying about how to interact with PwD and coping with the emotional impact of working with PwD and their families, particularly when involved in the diagnosis of dementia. On reflection, I realise that it was my anxieties about interacting with PwD that made me over-think it and forget how to interact on a basic human-to-human level. I now see that what PwD really need is for others to continue to communicate and interact with them in a human way and hence demonstrate their value and sense of worth, despite their diagnosis. I think this is particularly important given that dementia gradually erodes a person's cognitive and functional abilities such that they may lose the roles and responsibilities that may have once contributed to their self-esteem and sense of worth. By focusing on our relationships and interactions with PwD we can help to maintain their sense of self despite the deteriorating course of dementia.

On reflection, it has struck me that prior to clinical training I always thought about working with PwD in negative terms. I was always concerned with how difficult and upsetting it would be, rather than how exciting and rewarding it could be if I gave it a chance. It is upsetting to think that my negative feelings and attitudes towards PwD translated into my behaviour towards them on the hospital ward when I turned away rather than engaging with them. Nevertheless, this further highlights

the importance of educating the general public and tackling negative attitudes so that these do not translate into negative behaviours towards PwD.

3.3 Training Experiences

3.3.1 Older Adult Placement

Prior to starting my older adult placement I met my clinical supervisor and disclosed my concerns about coping with the emotional impact of working with PwD and their families. I was particularly concerned about conducting neuropsychological assessments and the possibility of having to relay a dementia diagnosis to clients and their families. My supervisor reassured me that this was a common concern. Indeed, it is acknowledged that health professionals who have to break such bad news can often feel uncomfortable about doing so for a variety of reasons including “fear of their own inadequacy in the face of uncontrollable disease” and “not feeling prepared to manage the patient’s anticipated emotional reactions” (DOH, Social Services and Public Safety, 2003, p.5). These reasons rang true for me and the knowledge that I was not alone in my fears was very comforting.

Furthermore, I found reading guidelines about how to break bad news increased my confidence in dealing with this task. On reflection I wonder whether people receiving a dementia diagnosis may also be helped by acknowledgment that people may have a range of feelings and reactions to being given this diagnosis, all of which are normal; and by guidance about how they might try to come to terms with the reality of dementia and move forward. Nevertheless, I think it is important to remember that each person is different and therefore how the news of a dementia

diagnosis is delivered should be tailored to the needs and wishes of each individual. In addition, although people receiving a dementia diagnosis may benefit from additional support and information, my placement experiences highlighted the importance of this being well timed and focused on a person's strengths and positive strategies for coping with the implications of the diagnosis rather than merely on the losses associated with dementia.

During the placement I found conducting neuropsychological assessments both daunting and upsetting, as I came to understand more about what a dementia diagnosis means, both in terms of the impact that the disease progression might have on PwD and those around them. I discussed these concerns in supervision and reflected upon my placement experiences in my reflective journal. I found that my worst fears were realised, in that the work did make me think about the impact dementia could have on me and my family and I did find it extremely upsetting to witness clients and families who were acutely distressed when faced with the reality of dementia. However, despite these fears coming true, I found that I was able to deal with them in a way that I could not have imagined previously. I was able to contain my emotion and put the needs of clients and families first by remaining professional and following their lead with regard to how best to support them. By approaching my fears head-on with a "can do" attitude I found I was able to cope much more easily than anticipated. This highlighted the importance of encouraging such an attitude in PwD as it may help them cope more effectively with the implications of their diagnosis.

My placement also involved co-facilitating a 'Coping with Forgetfulness' group for people with memory problems and their families. The PwD who attended had recently received their diagnosis and were coming to terms with the reality of what this would mean for themselves and their families. It was clear that this was a very emotional and anxiety provoking time for them and I found it difficult to contain my own emotions at times as the stories and worries they shared made me think even more about my own future and the possibility of dementia. Nevertheless, I could see the usefulness of sharing their fears and concerns with each other and in doing so seeking support that could only really come from other people with a shared experience. It showed me the immense value of peer support not only for clients and families, but also for professionals coping with the emotional impact of their work.

As I dealt with the emotional impact of working with PwD, I began to think about the experiences of other professionals working with this client group. I felt very fortunate to have access to many different sources of support including supervision, reflective practice, and the support of my peers and course team. It made me wonder whether other professionals had access to the same support systems and in particular I wondered about the experiences of staff working directly with PwD in care settings. I recalled working as support worker in a mental health hospital during my university placement year. In this role I received almost no training and whilst I did have supervision, this was rare and did not incorporate space to reflect on the impact of the role on my own wellbeing. It made me wonder whether staff working with PwD in care settings may have similar experiences of

training and lack of support in their roles which is how the idea for my empirical paper came to light. I wanted to find out what it was like for such staff and in particular about the emotional impact of the work and how they coped with this.

3.3.2 Research

Given my initial experiences of seeing how hospital nursing staff interacted with PwD, I wondered whether staff working with PwD in residential care homes would demonstrate a similar attitude. When planning my research I spent time considering my own views and opinions and completed a bracketing interview in which my research supervisor interviewed me in order to identify my expectations about what staff might say about their experiences. I found that I had low expectations about how educated and well-informed staff would be about dementia and how to work effectively with PwD, and that I also had low expectations about how well supported they would be in their role in terms of supervision and support from colleagues.

I think these low expectations stemmed in part from my voluntary experiences in which the nursing staff's attitude seemed to reflect a lack of understanding about dementia and how to interact with PwD, but also my own experiences of inadequate training and supervision as a support worker. It seemed that, although more than 10 years had passed between my voluntary work and my doctoral research, I still did not believe that staff working with PwD would be any better trained or supported than I or the hospital staff had been. Nevertheless, when conducting my research I was inspired by the genuine enthusiasm staff expressed about their role. In contrast to my experiences of working alongside hospital ward

staff, I found the staff working in residential care homes to be highly knowledgeable about dementia and driven to treat PwD first and foremost as people rather than perceiving them through the lens of their diagnostic label. I was shocked to hear how well supported they felt and to learn that they had all completed at least a Level 2 National Vocational Qualification (NVQ) related to their role.

This made me wonder whether my low expectations of the training and support that staff working with PwD in this setting would receive had indeed been clouded by my own negative previous experiences or whether this level of support and training was unique to the residential homes in which I recruited. Indeed, I wondered whether there are differences between private and National Health Service (NHS) care providers as the government have recently outlined their vision that by 2020 all NHS staff including those providing care and support to PwD will have received dementia training appropriate to their role (DOH, 2015), indicating that adequate dementia training is not consistently in place across NHS settings currently.

Furthermore, I wonder whether the differences I observed reflect the different contexts and philosophies of care between acute hospitals and long-term care settings for PwD. For example, acute hospitals have high turnover with a focus on symptom improvement whereas long-term care settings may have a care philosophy more focused on living well with dementia which may influence the attitude of staff working in these different settings. In addition, given my current role I wonder whether I now have a different perspective in light of my additional training and experiences. This has highlighted the importance of acknowledging the

differences in the roles, training and experience of different professionals and the value of coming together to share knowledge and learn from each other.

3.3.3 Teaching

My doctoral training has included delivering teaching to my peers and to students completing a masters degree course at The University of Warwick. On both occasions I chose to present on topics related to PwD which I think highlights my increased interest and enthusiasm for working with this client group since gaining more experience and knowledge in this area. I found that searching the literature and planning these teaching sessions was not a chore because I was genuinely interested in the topic area. This enthusiasm has highlighted just how much my perceptions about PwD have changed and become increasingly positive over time in light of my increased knowledge and experience. I wonder whether this is a common experience since it mirrors the finding from my empirical paper in which staff indicated that their perceptions of both older people and PwD had changed in a positive way following their occupational experiences. Again, I feel that this underlines the importance of the general population and care staff being better informed about dementia and having the opportunity to interact and engage with PwD.

During the masters teaching the students asked questions about my experiences of working with PwD and expressed their concerns about working with this client group. Having once had the same anxieties myself I was able to relate to their concerns. However, I realised that I felt very different to how I felt when I was more inexperienced and in a similar position to them. When answering their questions it

struck me just how much my perceptions of working with PwD had changed to the point where I could reassure others as opposed to needing reassurance myself. I found myself explaining my own initial anxieties but also talking about the journey I had taken in confronting my fears and reflecting upon how my new knowledge and experiences did not fit with my previous attitudes about working with PwD.

3.3.4 Summary

My doctoral training experiences have forced me to confront my fears about working with PwD despite the emotional impact of the work. As my knowledge increased and I was supported through these experiences I came to see that working with PwD was not as frightening as I had once imagined. In fact, I grew to love working with PwD and decided to conduct my research and deliver teaching on this topic. Overall, I think my attitude change is reflective of the different cultures in which I worked prior to and during training and how they have taught me to think about and interact with PwD. I think that these two different cultures are broadly similar to the two cultures outlined by Kitwood (1997), the 'old culture' which he describes as one of alienation in which PwD were unable to flourish and often reduced to isolation and despair; and the 'new culture' which he describes as one which does not pathologise PwD but instead recognises their uniqueness and in which care is concerned with maintaining personhood (Kitwood, 1997, pp. 135-137). In line with this I now recognise the value of treating PwD in a person-centred way rather than through the lens of their diagnosis.

Conducting my research has further contributed to the overall change in my attitude. My literature review paper findings have shown me that what families

value most is staff treating both them and their relatives with dementia as individuals; with kindness and respect whilst paying attention to their individual needs. This has shown me that working with PwD is something that I *can* do, as I do possess the basic human qualities required to build effective relationships with PwD and their families. Furthermore, my empirical paper findings have highlighted just how rewarding it can be when such relationships are formed with PwD.

This transition in my attitude has been an important learning point for me and one that I intend to transfer to other situations in which I may have negative initial impressions or anxieties. It has reminded me that despite my preconceptions or concerns I should always keep an open mind and confront my fears head-on by taking opportunities to enhance my knowledge and broaden my experiences. I believe this will be the key to enhance my personal and professional development as I progress from clinical training to a newly qualified clinical psychologist.

3.4 Future Directions

As my perceptions of working with PwD have changed over the past few years, I have become more interested in working with this population upon qualification. Whilst this was something I had not considered prior to training, after undertaking my older adult placement and conducting my research my enthusiasm for working with PwD has greatly increased. I no longer think about working with PwD in a negative way, focusing only on how difficult this might be or the negative impact that it might have on me. Whilst I am aware that working with this client group would still be difficult and would indeed have an emotional impact on me, I no longer see this as off-putting and something to shy away from. Conversely, I see it

as something that would continue to challenge and inspire me and recognise that part of what draws me to work with PwD *is* this emotional impact.

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Appendix A

Author Instructions for *Dementia*

Manuscript Submission Guidelines

Dementia: The International Journal of Social Research and Practice

Dementia publishes original research or original contributions to the existing literature on social research and dementia. The journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.



1. Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

2. Article types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Dementia also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 750-1500 words.

The journal also publishes book reviews.

3. How to submit your manuscript

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

Dementia is hosted on SAGE track a web based online submission and peer review system powered by ScholarOne Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit <http://mc.manuscriptcentral.com/dementia> to login and submit your article online.

IMPORTANT: If you are a new user, you will first need to create an account. Submissions should be made by logging in and selecting the Author Center and the 'Click here to Submit a New Manuscript' option. Follow the instructions on each page, clicking the 'Next' button on each screen to save your work and advance to the next screen. If at any stage you have any questions or require the user guide, please use the '[Online Help](#)' button at the top right of every screen.

All original papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

Innovative Practice papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Jo Moriarty jo.moriarty@kcl.ac.uk.

Books for review should be sent to: Book Review Editor ♦ Dementia, Heather Wilkinson, College of Humanities & Social Science, University of Edinburgh, 55-56 George Square, Edinburgh, EH8 9JU, UK. Email: hwilkins@staffmail.ed.ac.uk

4. Journal contributor's publishing agreement

Before publication SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. For more information please visit our [Frequently Asked Questions](#) on the SAGE Journal Author Gateway.

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4.1 SAGE Choice and Open Access

If you or your funder wish your article to be freely available online to non subscribers immediately upon publication (gold open access), you can opt for it to be included in SAGE *Choice*, subject to payment of a publication fee. The manuscript submission and peer review procedure is unchanged. On acceptance of your article, you will be asked to let SAGE know directly if you are choosing SAGE *Choice*. To check journal eligibility and the publication fee, please visit [SAGE Choice](#). For more information on open access options and compliance at SAGE, including self author archiving deposits (green open access) visit [SAGE Publishing Policies](#) on our Journal Author Gateway.

5. Declaration of conflicting interests

Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. It is the policy of *Dementia* to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please include any declaration at the end of your manuscript after any acknowledgements and prior to the references, under a heading 'Declaration of Conflicting Interests'. If no declaration is made the following will be printed under this heading in your article: 'None Declared'. Alternatively, you may wish to state that 'The Author(s) declare(s) that there is no conflict of interest'.

When making a declaration the disclosure information must be specific and include any financial relationship that all authors of the article has with any sponsoring organization and the for-profit interests the organization represents, and with any for-profit product discussed or implied in the text of the article.

Any commercial or financial involvements that might represent an appearance of a conflict of interest need to be additionally disclosed in the covering letter accompanying your article to assist the Editor in evaluating whether sufficient disclosure has been made within the Declaration of Conflicting Interests provided in the article.

Please acknowledge the name(s) of any medical writers who contributed to your article. With multiple authors, please indicate whether contributions were equal, or indicate who contributed what to the article.

For more information please visit the [SAGE Journal Author Gateway](#).

6. Other conventions

6.1 Informed consent

Submitted manuscripts should be arranged according to the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals". The full document is available at <http://icmje.org>. When submitting a paper, the author should always make a full statement to the Editor about all submissions and previous reports that might be regarded as redundant or duplicate publication of the same or very similar work.

Ethical considerations: All research on human subjects must have been approved by the appropriate research body in accordance with national requirements and must conform to the principles embodied in the Declaration of Helsinki (<http://www.wma.net>) as well as to the International Ethical Guidelines for Biomedical Research Involving Human Subjects and the International Guidelines for Ethical Review for Epidemiological Studies (<http://www.cioms.ch>). An appropriate statement about ethical considerations, if applicable, should be included in the methods section of the paper.

6.2 Ethics

When reporting experiments on human subjects, indicate whether the procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional or regional) or with the Declaration of Helsinki 1975, revised Hong Kong 1989. Do not use patients' names, initials or hospital numbers, especially in illustrative material. When reporting experiments on animals, indicate which guideline/law on the care and use of laboratory animals was followed.

7. Acknowledgements

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

7.1 Funding Acknowledgement

To comply with the guidance for Research Funders, Authors and Publishers issued by the Research Information Network (RIN), *Dementia* additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit [Funding Acknowledgement](#) on the SAGE Journal Author Gateway for funding acknowledgement guidelines.

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9. Manuscript style

9.1 File types

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, DOCX, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork [and supplemental files] below.

9.2 Journal Style

Dementia conforms to the SAGE house style. [Click here](#) to review guidelines on SAGE UK House Style.

Lengthy quotations (over 40 words) should be displayed and indented in the text.

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. demented). Language that might be deemed sexist or racist should not be used.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

9.3 Reference Style

Dementia adheres to the APA reference style. [Click here](#) to review the guidelines on APA to ensure your manuscript conforms to this reference style.

9.4. Manuscript Preparation

The text should be double-spaced throughout with generous left and right-hand margins. Brief articles should be up to 3000 words and more substantial articles between 5000 and 8000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Innovative practice papers should be between 750-1500 words.

9.4.1 Keywords and Abstracts: Helping readers find your article online

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on [How to Help Readers Find Your Article Online](#). The abstract should be 100-150 words, and up to five keywords should be supplied in alphabetical order.

9.4.2 Corresponding Author Contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

9.4.3 Guidelines for submitting artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

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This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's [Guidelines for Authors on Supplemental Files](#).

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Non-English speaking authors who would like to refine their use of language in their manuscripts might consider using a professional editing service. Visit [English Language Editing Services](#) for further information.

10. After acceptance

10.1 Proofs

We will email a PDF of the proofs to the corresponding author.

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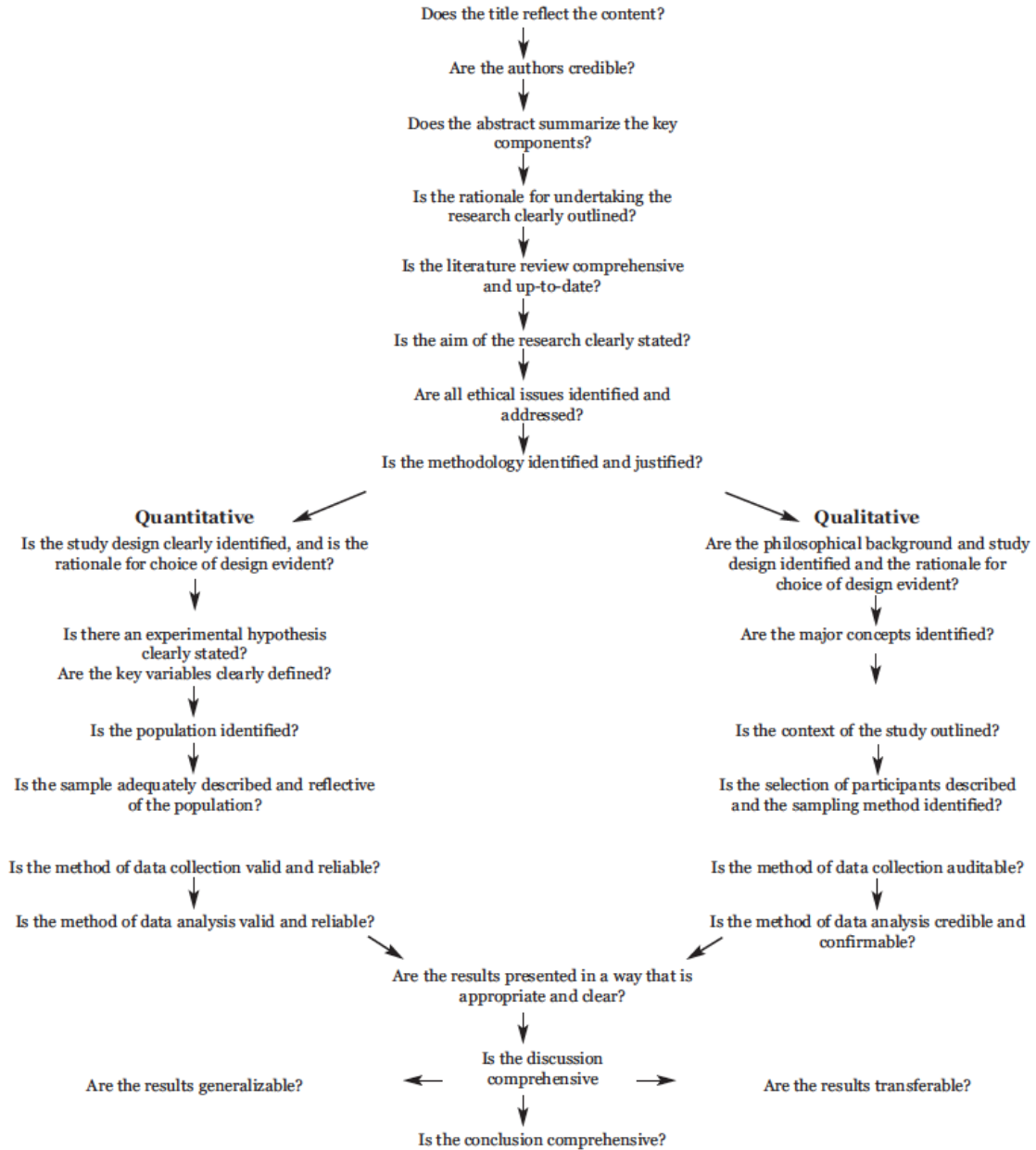
Dementia offers OnlineFirst, a feature offered through SAGE's electronic journal platform, SAGE Journals Online. It allows final revision articles (completed articles in queue for assignment to an upcoming issue) to be hosted online prior to their inclusion in a final print and online journal issue which significantly reduces the lead time between submission and publication. For more information please visit our [OnlineFirst Fact Sheet](#).

11. Further information

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office at dem.pra@sagepub.com.

Appendix B

Quality Appraisal Checklist



Caldwell et al., 2005, p. 50

Appendix C

Quality Appraisal Checklist Results

Met criterion = 2, partially met criterion =1, not met criterion =0

| Quality Framework | | Bramble et al (2008) | Duncan & Morgan (1994) | Edvardsson et al (2010) | Ejaz et al (2002) | Hertzberg & Ekman (2000) | Legault & Ducharme (2009) | Looman et al (1997) |
|---|---|----------------------|------------------------|-------------------------|-------------------|--------------------------|---------------------------|---------------------|
| 1. Does the title reflect the content? | | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| 2. Are the authors credible? | | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| 3. Does the abstract summarise the key components? | | Yes | Partially | Yes | Yes | Yes | Yes | Yes |
| 4. Is the rationale for undertaking the research clearly outlined? | | Yes | Partially | Yes | Yes | Yes | Yes | Yes |
| 5. Is the literature review comprehensive and up to date? | | Yes | Yes | Yes | Yes | Yes | Yes | Partially |
| 6. Is the aim of the research clearly stated? | | Yes | Partially | Yes | Yes | Yes | Yes | No |
| 7. Are all ethical issues identified and addressed? | | Partially | No | Partially | No | No | Yes | No |
| 8. Is the Methodology identified and justified? | | Yes | Yes | Partially | Partially | Yes | Yes | Partially |
| Quantitative | Qualitative | | | | | | | |
| 9. Is the study design clearly identified, and is the rationale for choice of design evident? | 9. Are the philosophical background and study design identified and the rationale for choice of design evident? | Yes | No | Partially | Yes | Yes | No | Partially |
| 10. Is there an experimental hypothesis clearly stated? Are the key | 10. Are the major concepts identified? | Yes | Yes | Partially | Yes | Yes | Yes | Yes |

| | | | | | | | | |
|--|--|-----------|-----------|-----------|-----------|-----------|-----------|-----------|
| variables clearly defined? | | | | | | | | |
| 11. Is the population identified? | 11. Is the context of the study outlined? | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| 12. Is the sample adequately described and reflective of the population? | 12. Is the selection of participants described and the sampling method identified? | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| 13. Is the method of data collection valid and reliable? | 13. Is the method of data collection auditable? | Yes | Yes | Partially | Yes | Yes | Partially | Yes |
| 14. Is the method of data analysis valid and reliable? | 14. Is the method of data analysis credible and confirmable? | Yes | Partially | Yes | Yes | Yes | Partially | Yes |
| 15. Are the results presented in a way that is appropriate and clear? | | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| 16. Is the discussion comprehensive? | | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| 17. Are the results generalizable? | 17. Are the results transferable? | Yes | Yes | Partially | Partially | Partially | Yes | Yes |
| 18. Is the conclusion comprehensive? | | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| Score | | 35 | 28 | 30 | 32 | 33 | 32 | 29 |

Met criterion = 2, partially met criterion =1, not met criterion =0

| Quality Framework | | MacDonald (2006) | Moyle et al (2014) | Mullin et al (2011) | Palmer (2012) | Piechniczek - Buczek et al (2007) | Shields Scott (1991) | van Zadelhoff et al (2011) |
|--|---|------------------|--------------------|---------------------|---------------|-----------------------------------|----------------------|----------------------------|
| 1. Does the title reflect the content? | | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| 2. Are the authors credible? | | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| 3. Does the abstract summarise the key components? | | Yes | Yes | Yes | Yes | Yes | No | Yes |
| 4. Is the rationale for undertaking the research clearly outlined? | | Yes | No | Yes | Partially | Yes | No | Yes |
| 5. Is the literature review comprehensive and up to date? | | Partially | Yes | Yes | Yes | Yes | No | Yes |
| 6. Is the aim of the research clearly stated? | | Yes | Yes | Yes | No | Partially | Partially | Yes |
| 7. Are all ethical issues identified and addressed? | | No | Partially | Yes | No | Partially | No | Yes |
| 8. Is the Methodology identified and justified? | | Yes | Partially | Yes | Yes | Partially | No | Yes |
| Quantitative | Qualitative | | | | | | | |
| 9. Is the study design clearly identified, and is the rationale for choice of design evident? | 9. Are the philosophical background and study design identified and the rationale for choice of design evident? | Partially | Yes | Partially | No | Yes | No | No |
| 10. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined? | 10. Are the major concepts identified? | Yes | Yes | Yes | Yes | Yes | No | No |
| 11. Is the population identified? | 11. Is the context of the study outlined? | Yes | Yes | Yes | Yes | Yes | Partially | Yes |
| 12. Is the sample adequately described | 12. Is the selection of participants described | Partially | Yes | Yes | No | No | No | No |

| | | | | | | | | |
|---|--|-----------|-----------|-----------|-----------|-----------|-----------|-----------|
| and reflective of the population? | and the sampling method identified? | | | | | | | |
| 13. Is the method of data collection valid and reliable? | 13. Is the method of data collection auditable? | Partially | Yes | Yes | Partially | Partially | No | No |
| 14. Is the method of data analysis valid and reliable? | 14. Is the method of data analysis credible and confirmable? | Partially | Yes | Yes | Yes | Partially | No | No |
| 15. Are the results presented in a way that is appropriate and clear? | | Yes | Yes | Yes | Yes | Yes | Partially | Yes |
| 16. Is the discussion comprehensive? | | Yes | Partially | Yes | Yes | Yes | No | Yes |
| 17. Are the results generalizable? | 17. Are the results transferable? | Partially | Yes | Yes | Partially | Yes | Yes | Partially |
| 18. Is the conclusion comprehensive? | | Yes | Yes | Yes | Yes | Yes | No | Yes |
| Score | | 28 | 31 | 35 | 25 | 29 | 9 | 25 |

Appendix D

Ethical Approval from Coventry University

CU Ethics <omis@coventry.ac.uk>

Tue 04/02/2014 09:26

Inbox

To: Katharine Poole <poolek4@coventry.ac.uk>



The following ethics request has been approved by Joanna Hemming. All the relevant documentation will be available for you to download within the next 24 hours. Please log back into Ethics and select the request from your listing. Select the Downloads tab to retrieve the documentation.

Please proceed with good ethics.

| | |
|----------------|--|
| Ref: | P18875 |
| Project Title: | The experiences of healthcare assistants working with clients with dementia in residential care homes. |
| Applicant: | Katharine Poole |
| Supervisor: | Tom Patterson |
| Module Code: | D44PY |
| Module Leader: | |

Go to ethics.coventry.ac.uk to view this request in more detail.

REGISTRY RESEARCH UNIT

ETHICS REVIEW FEEDBACK FORM

(Review feedback should be completed within 10 working days)

Name of applicant: Katharine Poole.....

Faculty/School/Department: [Faculty of Health and Life Sciences] Clinical Psychology

Research project title: The experiences of healthcare assistants working with clients with dementia in residential care homes.

| | |
|---|---|
| 1. Evaluation of the ethics of the proposal: | |
| This research proposal outlines appropriate procedures for all the ethical issues involved in carrying out the research. | |
| 2. Evaluation of the participant information sheet and consent form: | |
| The participant information sheet and consent form is appropriate for the study. | |
| 3. Recommendation: (Please indicate as appropriate and advise on any conditions. If there are any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer). | |
| <input checked="checked" type="checkbox"/> | Approved - no conditions attached |
| <input type="checkbox"/> | Approved with minor conditions (no need to re-submit) |
| <input type="checkbox"/> | Conditional upon the following – please use additional sheets if necessary (please re-submit application) |
| <input type="checkbox"/> | Rejected for the following reason(s) – please use other side if necessary |
| <input type="checkbox"/> | Not required |

Name of reviewer: Anonymous.....

Date: 03/02/2014.....

Appendix E

Pilot Focus Group Letter to Care Home Manager

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Programme Director
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Dr Eve Knight
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THE UNIVERSITY OF
WARWICK



Clinical Psychology Doctorate
Faculty of Health and Life Sciences
James Starley Building
Coventry University
Priory Street
Coventry
CV1 5FB

14th March 2014

Dear Sir/Madam

The experiences of healthcare assistants working with clients with dementia in residential care homes

I am a Trainee Clinical Psychologist completing my doctoral thesis at Coventry University and The University of Warwick under the supervision of Dr Tom Patterson (Clinical Psychologist/Academic Director, Clinical Psychology Doctorate) and Jane Muers (Clinical Psychologist).

I am currently conducting research exploring the experiences of staff members who work with clients with dementia in residential care homes. I am particularly interested in hearing about the experiences of healthcare assistants or equivalent because there is a lack of research in this area. I am therefore looking for staff members who do not have a nursing qualification to volunteer to take part in my research. It is hoped that the research will help to identify ways in which staff can be supported in carrying out their role.

Therefore, I am currently contacting you and managers of other local residential care homes to let you know about my study and to see if you are willing to allow your staff members to participate.

There are two parts to this study – the first part comprises a pilot focus group involving 2-3 members of staff and the second part comprises individual staff interviews. I would like to invite your staff to take part in both (i.e. some members of staff to take part in the focus group and other members of staff to take part in the individual interviews). However, initially I would like to invite your staff to take part in the focus group which forms the first part of the study.

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Head of Department of Psychology
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If you are interested in finding out more about this research I have enclosed an information sheet that describes the study and what participation would involve. It also contains my contact details should you have any questions about the study or if you would like to find out more. I hope that you find this information interesting.

I will contact you by telephone in 1-2 weeks time to answer any questions you may have and to discuss whether you would be happy for your eligible staff members to take part.

Thank you for your time.

Yours sincerely

Katharine Poole
Trainee Clinical Psychologist
Coventry and Warwick Universities

Appendix F

Pilot Focus Group Participant Information Sheet

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THE UNIVERSITY OF
WARWICK



The experiences of healthcare assistants working with clients with dementia in residential care homes

FOCUS GROUP PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully. Please feel free to contact me if you have any questions or if anything is unclear.

-What is the purpose of the study?

This study is looking at the experiences of healthcare assistants or equivalent who work with clients with dementia in residential care homes. Previous research has indicated that caring for people with dementia can be a rewarding but also a difficult and challenging job. However, there is little research that explores in depth what it is like for staff who care for clients with dementia in residential care homes. Therefore, this research aims to explore the first-hand experiences of these staff members. It is hoped that by gaining greater insight into the experiences of healthcare assistants or equivalent, the findings of this study may help to identify how staff can be best supported to carry out their role.

In order to find out about staff members' experiences of working with clients with dementia, this research will be conducted in two parts. Firstly, a focus group will be conducted with 2-3 healthcare assistants or equivalent to find out about their experiences of working with clients with dementia in residential care homes. Following this, the data obtained in the focus group will be analysed and used to identify which questions to ask staff members in the second part of the study, in which approximately 8-12 healthcare assistants or equivalent will be interviewed individually. You are being invited to take part in the focus group which forms the first part of this study.

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-Why have I been approached?

Members of staff who are not qualified nurses are being invited to take part. I am hoping to run a focus group with approximately 2-3 people to find out about their experiences of working with clients with dementia. This is in preparation for conducting individual interviews with more staff members. Therefore, the information obtained in the focus group will be used to decide which questions to ask in the individual interviews later in the study.

-What will happen in the study?

This study will involve participants attending a focus group interview being conducted by the researcher for approximately 1 hour at their place of work at a time convenient to them. The focus group will be audiotaped and transcribed for analysis purposes but all information provided will remain confidential and will only be accessible to the researcher and their supervisors. Each participant will be given a pseudonym and will not be identifiable to the supervisors of the researcher.

Prior to participating in the focus group you will be asked to re-read this information sheet and you will be given the opportunity to ask any questions you may have. You will then be asked to sign a consent form to take part. Following this, you will be asked to fill in a demographic information form to enable us to gain basic information about you and your role. All of this information will be kept confidential and will be anonymised in the final report so that you will not be identifiable.

-Do I have to take part?

It is up to you whether or not you want to participate in the focus group. There are absolutely no negative consequences if you decide not to take part. If you do decide to take part in the research you will need to sign a consent form. You will be given a copy of this. No other member of staff will be informed about whether or not you have participated.

-What if I change my mind?

If you decide to participate in the research and then later change your mind, you have the right to withdraw from the study and have your data destroyed at any time within two weeks of the focus group taking place. You do not have to give a reason for withdrawing. Once your data has been incorporated into the analysis it will not be possible for it to be withdrawn. If you do not withdraw your consent for your data to be included in the analysis within the two-week time frame it will be incorporated into the write-up. However, all data will be kept confidential and will be anonymised so that you are not identifiable.

-Confidentiality

All data collected will be held in accordance with the Data Protection Act (1998). Your information will be kept in a locked filing cabinet. When the research report is published any information relating to you will be anonymised so that you are not identifiable.

-After the study

After the study has been completed and the data has been analysed you will be offered the opportunity to receive a summary of the main findings (approximate date September 2015). If you wish to receive a copy of the main findings please indicate this by ticking the relevant box on the consent form. The research results will be written up as a report. This will be submitted as part of a Doctoral Course in Clinical Psychology at the Universities of Coventry and Warwick and may also be submitted for publication. Any information contained within the report will remain confidential and will be fully anonymised.

It is important to note that in the unlikely event that any issues were raised that were regarding risk to yourself or to clients, the researcher would be obliged to inform your manager.

-What are the possible disadvantages of taking part?

The focus group is not designed to upset or distress you in any way. However, it is possible that issues may be raised in the focus group that cause you to feel upset. If this is the case, you will be offered the opportunity to take a break or to discontinue the interview. If you do feel upset or distressed following the focus group you will be advised to seek support from your GP.

-What are the possible benefits of taking part?

By taking part you will be able to tell your story about your job and what it is like for you to care for clients with dementia. Taking part in this focus group will help to develop a greater understanding of what it is like for healthcare assistants working with clients with dementia in residential care homes. It will enable the researcher to identify which questions to ask participants in the individual interviews later in the study.

-Who should I contact for further information?

If you have any questions or you would like further information please contact me:

Katharine Poole

Clinical Psychology Doctorate
Faculty of Health and Life Sciences
James Starley Building
Coventry University
Priory Street
Coventry
CV1 5FB

Telephone: 024 7688 8328

Fax: 024 7688 8702

Email: poolek4@uni.coventry.ac.uk

Appendix G

Pilot Focus Group Participant Consent Form

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Dr Eve Knight
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THE UNIVERSITY OF
WARWICK



The experiences of healthcare assistants working with clients with dementia in residential care homes

FOCUS GROUP PARTICIPANT CONSENT FORM

Name of Researcher: Katharine Poole

Please initial
each box:

1. I confirm that I have read and understood the information sheet for the above study. ☐
2. I have been given the opportunity to ask questions about the research and what my contribution will involve. Any questions I had have been answered satisfactorily. ☐
3. I understand that my participation in the research is entirely voluntary and that I am free to withdraw from the study at any time within two weeks of the focus group taking place without having to give a reason. I understand that should I decide to withdraw within the two week time frame following the focus group my data will be destroyed. ☐
4. I give my permission for the focus group I take part in to be audiotaped and transcribed. ☐
5. I understand that all documents relating to the research including audio recordings of the focus group will not be identified by name and will be kept confidential. ☐
6. I understand that the individuals supervising this research will look at the transcript of the focus group I take part in but that I will not be identifiable to them. ☐

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7. I agree to participate in the above study.

☐

☐ Please tick if you wish to receive a copy of the main findings (available approx. September 2015).

Signed:

Name:

Date:

Signature of Researcher:

Date:

Appendix H

Pilot Focus Group Interview Schedule

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Dr Eve Knight
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The experiences of healthcare assistants working with clients with dementia in residential care homes

Pilot Study: Focus Group Interview Schedule

Researcher: Thank you for agreeing to take part in this focus group. As you know I am interested in what you have to say about your role and what it is like for you to work with clients with dementia in residential care homes. It is likely that this meeting will take about an hour, but if at any time you would like to stop then please let me know. Before we begin I would like to remind you of the rights that you have when you agree to participate in research like this:

You have the right to withdraw from the study at any time up to two weeks after this focus group. If you choose to withdraw within this time frame your data from this focus group will be destroyed. I will be recording our discussion today using a Dictaphone and afterwards I will transcribe our discussion and will then destroy the recording. The transcription of this focus group will be anonymous (i.e. it will not be identifiable to you). The focus group transcript will be kept for approximately five years, after which time it will be destroyed.

Do you have any questions about this or about the format of the focus group today?

- 1. Can you tell me about your role/what your job involves?**
- 2. How do you find working with clients with dementia?**
- 3. Can you comment on aspects of your role that you like and enjoy?**
- 4. Can you comment on aspects of your role that you dislike or find difficult?**
- 5. Is there anything else that you would like to say about your experience of working with clients with dementia in residential care homes?**

Prompts:

-Could you say a bit more about that?

-Can you give me an example of that?

-What do you mean by that?

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Appendix I

Pilot Focus Group Themes

| Main Themes | Subthemes |
|---------------------------|--|
| Role and Responsibilities | Direct client contact Client-related tasks Contact with families Staffing Supervisory role Training/CPD |
| Difficulties | Negative feelings towards the job Witnessing/hearing upsetting things Frustrations with hospital care Communication difficulties Difficult situations Drain on your resources |
| Enjoyable Aspects | Positive feelings towards the job Having fun Helping/Giving back Improving quality of life |

Appendix J

Main Study Letter to Care Home Managers

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Clinical Psychology Doctorate
Faculty of Health and Life Sciences
James Starley Building
Coventry University
Priory Street
Coventry
CV1 5FB

14th July 2014

Dear Sir/Madam

The experiences of healthcare assistants working with clients with dementia in residential care homes

I am a Trainee Clinical Psychologist completing my doctoral thesis at Coventry University and The University of Warwick under the supervision of Dr Tom Patterson (Clinical Psychologist/Academic Director, Clinical Psychology Doctorate) and Jane Muers (Clinical Psychologist).

I am currently conducting research exploring the experiences of staff members who work with clients with dementia in residential care homes. I am particularly interested in hearing about the experiences of healthcare assistants or equivalent because there is a lack of research in this area. I am therefore looking for staff members who do not have a nursing qualification to volunteer to take part in my research. It is hoped that it will help to identify ways in which staff can be supported in carrying out their role.

Therefore, I am currently contacting you and managers of other local residential care homes to let you know about my study and to see if you are willing to allow your staff members to participate. If you are interested in finding out more about this research I have enclosed an information sheet that describes the study and what participation would involve. It also contains my contact details should you have any questions about the study or if you would like to find out more.

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I hope that you find this information interesting. I will contact you by telephone in 1-2 weeks time to answer any questions you may have and to discuss whether you would be happy for your eligible staff members to take part.

Thank you for your time.

Yours sincerely

Katharine Poole
Trainee Clinical Psychologist
Coventry and Warwick Universities

Appendix K

Main Study Participant Information Sheet

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The experiences of healthcare assistants working with clients with dementia in residential care homes

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully. Please feel free to contact me if you have any questions or if anything is unclear.

-What is the purpose of the study?

This study is looking at the experiences of healthcare assistants or equivalent who work with clients with dementia in residential care homes. Previous research has indicated that caring for people with dementia can be a rewarding but also a difficult and challenging job. However, there is little research that explores in depth what it is like for staff who care for clients with dementia in residential care homes. Therefore, this research aims to explore the first-hand experiences of these staff members. It is hoped that by gaining greater insight into the experiences of staff members, the findings of this study may help to identify how staff can be best supported to carry out their role.

-Why have I been approached?

Members of staff who are not qualified nurses are being invited to take part. I am hoping to speak to approximately 8-12 people about their experiences of working with clients with dementia.

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-What will happen in the study?

This study will involve participants being interviewed individually by the researcher for approximately 45 minutes at their place of work at a time convenient to them. Interviews will be audiotaped and transcribed for analysis purposes but all information provided will remain confidential and will only be accessible to the researcher and their supervisors. Each participant will be given a pseudonym and will not be identifiable to the supervisors of the researcher.

Prior to starting the interview you will be asked to re-read this information sheet and you will be given the opportunity to ask any questions you may have. You will then be asked to sign a consent form to take part. Following this, you will be asked to fill in a demographic information form to enable us to gain basic information about you and your role. All of this information will be kept confidential and will be anonymised in the final report so that you will not be identifiable.

-Do I have to take part?

It is up to you whether or not you want to participate in the study. There are absolutely no negative consequences if you decide not to take part. If you do decide to take part in the research you will need to sign a consent form. You will be given a copy of this. No other member of staff will be informed about whether or not you have participated.

-What if I change my mind?

If you decide to participate in the research and then later change your mind, you have the right to withdraw from the study and have your data destroyed at any time up until the point of the final write-up (15th January 2015). You do not have to give a reason for withdrawing. Once your data has been incorporated into the analysis it will not be possible for it to be withdrawn. If you do not withdraw your consent for your data to be included in the analysis before 15th January 2015 it will be incorporated into the final write-up. However, all data will be kept confidential and will be anonymised so that you are not identifiable.

-Confidentiality

All data collected will be held in accordance with the Data Protection Act (1998). Your information will be kept in a locked filing cabinet. When the research report is published any information relating to you will be anonymised so that you are not identifiable.

-After the study

After the interviews have been completed and the data has been analysed you will be offered the opportunity to receive a summary of the main findings (approximate date September 2015). If you wish to receive a copy of the main findings please indicate this by ticking the relevant box on the consent form. The research results will be written up as a report. This will be submitted as part of a Doctoral Course in Clinical Psychology at the Universities of Coventry and Warwick and may also be submitted for publication. Any

information contained within the report will remain confidential and will be fully anonymised.

It is important to note that in the unlikely event that any issues were raised that were regarding risk to yourself or to clients, the researcher would be obliged to inform your manager.

-What are the possible disadvantages of taking part?

The interview is not designed to upset or distress you in any way. However, it is possible that issues may be raised in the interview that cause you to feel upset. If this is the case, you will be offered the opportunity to take a break or to discontinue the interview. If you do feel upset or distressed following the interview you will be advised to seek support from your GP.

-What are the possible benefits of taking part?

By taking part you will be able to tell your story about your job and what it is like for you to care for clients with dementia. Taking part in this research will help to develop a greater understanding of what it is like for healthcare assistants working with clients with dementia in residential care homes. It would highlight some of the important issues for staff working in this setting. It is hoped that this will help to identify how best to help and support healthcare assistants or equivalent who work with clients with dementia.

-Who should I contact for further information?

If you have any questions or you would like further information please contact me:

Katharine Poole

Clinical Psychology Doctorate
Faculty of Health and Life Sciences
James Starley Building
Coventry University
Priory Street
Coventry
CV1 5FB

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Email: poolek4@uni.coventry.ac.uk

Appendix L

Main Study Participant Consent Form

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THE UNIVERSITY OF
WARWICK



The experiences of healthcare assistants working with clients with dementia in residential care homes

PARTICIPANT CONSENT FORM

Name of Researcher: Katharine Poole

Please initial
each box:

1. I confirm that I have read and understood the information sheet for the above study. ☐
2. I have been given the opportunity to ask questions about the research and what my contribution will involve. Any questions I had have been answered satisfactorily. ☐
3. I understand that my participation in the research is entirely voluntary and that I am free to withdraw from the study at any time prior to the final write-up (15th January 2015) without having to give a reason. I understand that should I decide to withdraw prior to the final write-up my data will be destroyed. ☐
4. I give my permission for the interview I take part in to be audiotaped and transcribed. ☐
5. I understand that all documents relating to the research including audio recordings of the interview will not be identified by name and will be kept confidential. ☐
6. I understand that the individuals supervising this research will look at the transcript of my interview but that I will not be identifiable to them. ☐

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Head of Department of Psychology
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

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7. I agree to participate in the above study.

☐

☐ Please tick if you wish to receive a copy of the main findings (available approx. September 2015).

Signed:

Name:

Date:

Signature of Researcher:

Date:

Appendix M

Participant Demographic Sheet

Coventry University
Priory Street, Coventry CV1 5FB
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Dr Eve Knight
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The experiences of healthcare assistants working with clients with dementia in residential care homes

PARTICIPANT DEMOGRAPHIC SHEET

Name:

Gender: Male Female

Age:

First Language:

Job Title:

Length of time in current job (in years): ____ years ____ months

Length of experience in care sector (in years): ____ years ____ months

Please list any care qualifications you have:

Length of experience caring for clients with dementia (in years): ____ years ____ months

Average working hours per week currently:

Shift Pattern: (please tick one) ☐ Days ☐ Nights ☐ Days and Nights

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Ethnicity: (please tick one)

White

- ☐ English/Welsh/ Scottish/Northern Irish/British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other White background

Asian / Asian British

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian background

Religion: (please tick one)

- ☐ No religion
- ☐ Christian
- ☐ Buddhist
- ☐ Hindu

Mixed / Multiple ethnic groups

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed / Multiple ethnic background

Black / African / Caribbean / Black British

- ☐ African
- ☐ Caribbean
- ☐ Any other Black / African / Caribbean background

Other ethnic group

- ☐ Arab
- ☐ Any other ethnic group

- ☐ Muslim
- ☐ Sikh
- ☐ Jewish
- ☐ Any other religion, please describe:

Appendix N

Main Study Interview Schedule

Coventry University
Priory Street, Coventry CV1 5FB
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Fax 024 7688 8702

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Doctorate Course in Clinical Psychology
Dr Eve Knight
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THE UNIVERSITY OF
WARWICK



The experiences of healthcare assistants working with clients with dementia in residential care homes

Interview Schedule

Researcher: Thank you for agreeing to take part in this interview. As you know I am interested in what you have to say about your role and what it is like for you to work with clients with dementia in residential care homes. It is likely that this meeting will take about an hour, but if at any time you would like to stop then please let me know. Before we begin I would like to remind you of the rights that you have when you agree to participate in research like this:

You have the right to withdraw from the study at any time up to 15th January 2015. If you choose to withdraw within this time frame your data from this interview will be destroyed. I will be recording our discussion today using a Dictaphone and afterwards I will transcribe our discussion and will then destroy the recording. The transcription of this interview will be anonymous (i.e. it will not be identifiable to you). The interview transcript will be kept for approximately five years, after which time it will be destroyed.

Do you have any questions about this or about the format of the interview today?

- 1. Can you tell me a bit about how you came to work here and what your role involves?**

Prompts

- What drew you towards working with clients with dementia in this setting?
- Could you describe a typical shift?
- In what ways do you help clients with dementia?

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Head of Department of Psychology
Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

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2. Can you comment on aspects of your role that you like and enjoy?

Prompts

- What, if any, are the good things about working with clients with dementia?
- Can you give an example?

3. Can you comment on aspects of your role that you dislike or find difficult?

Prompts

- What, if anything, is hard or difficult about working with the clients with dementia that you work with?
- What, if any, are the not so nice things about working with clients with dementia?
- Do you seek any support at times when you find things difficult?

4. One of the roles in care homes can involve end of life care. Is this relevant to you? If so, can you talk about your experience of this?

Prompts

- How have you found being involved in end of life care?
- Has there been anything about end of life care that you have found difficult?
- What has helped or supported you when dealing with end of life care?

5. What does working with people with dementia bring up for you? (e.g. positive or negative feelings)

Prompts

- Some people say that there is an emotional impact of the work. Does this fit with your experience?

6. Can you tell me a bit about how you personally deal with/cope with the emotional impact of the job?

Prompts

- How do you cope when you experience negative emotions related to your role?

7. Is there anything else that you would like to say about your experience of working with clients with dementia?

General prompts

- Can you say a bit more about that?
- Can you give me an example of that?

Appendix O

Interpretative Phenomenological Analysis – Data Analysis Steps

| Step | Description |
|------|--|
| 1 | The close, line-by-line analysis of the experiential claims, concerns and understandings of each participant |
| 2 | The identification of emergent patterns (i.e. themes) within this experiential material, emphasising both convergence and divergence, commonality and nuance, usually first for single cases, and then subsequently across multiple cases |
| 3 | The development of a 'dialogue' between the researchers, the coded data, and their psychological knowledge, about what it might mean for participants to have these concerns, in this context, leading in turn to the development of a more interpretative account |
| 4 | The development of a structure, frame or gestalt which illustrates the relationships between themes |
| 5 | The organisation of all this material in a format which allows for analysed data to be traced right through the process, from initial comments on the transcript, through initial clustering and thematic development, into the final structure of themes |
| 6 | The use of supervision, collaboration, or audit to help test and develop the coherence and plausibility of the interpretation |
| 7 | The development of a full narrative, evidence by a detailed commentary on data extracts, which takes the reader through this interpretation, usually theme-by-theme, and is often supported by some form of visual guide (a simple structure, diagram or table) |
| 8 | Reflection on one's own perceptions, conceptions and processes |

Data analysis steps in Interpretative Phenomenological Analysis (IPA) as outlined by Smith, Flowers and Larkin, 2009, pp.79-80.

Appendix P

Initial Coding Transcript Example

| | | | | |
|--|------|---|--|---|
| | | | | Difficult to balance needs of clients with need to do paperwork |
| | 104. | that then that can be quite hard. But knowing that you've got people with | | |
| But knowing that you have people who don't have any structure, their needs are more important than paperwork. | 105. | dementia and stuff...sometimes their needs are more important. Obviously | | Sometimes have to put the needs of clients first as they are more important |
| | 106. | when you're on the floor and doing paperwork. So sometimes the needs of | | |
| | 107. | the people on the floor will just take over everything if that makes sense. | | Juggling act to get the balance right? |
| | 108. | And then you're just focused on those few people at that point in time. | | Resentful of the amount of paperwork? |
| | 109. | | | |
| Sometimes their needs will just take over everything then you're just focused on those few people at that point in time. | 110. | Interviewer: Yea. Are there any not so nice things about working with | | Links with idea of responsibility - staff having to make a judgement call about what it is most important to do |
| | 111. | clients with dementia? | | |
| | 112. | | | |
| | 113. | P5: It can be quite upsetting. Erm... especially when they don't remember | | |
| It can be quite upsetting especially if they can't remember something or they see a relative but don't know a child who they are | 114. | certain things about their lives. If they know something but they can't | | Upsetting and emotional to watch clients not remember and to have to witness the impact on them and families. |
| | 115. | remember it fully or... if they see their relative and they don't have a clue | | |
| | 116. | who they are. Sometimes the relative gets upset. It can be quite emotional | | Upsetting and emotional to have to deal with it. |
| | 117. | then because you're trying to calm both of them down. Yea... it's just | | |
| Sometimes relatives get upset if they can't remember them | 118. | mainly when they... just when they forget things or when they get | | Distressing to witness the impact of the dementia on the client and to be the carer who has to try to deal with it (when it can't be fixed) sense of helplessness |
| It can be quite emotional if you have to tell a person and their relative about | 119. | frustrated because they forget things and then they get angry. It can be | | |
| | 120. | quite emotional then. | | |
| | 121. | | | |
| It can be quite emotional if you have to tell a person and their relative about | 122. | Interviewer: And do you seek any support at times when you find it | | |
| | 123. | difficult? | | |
| It can be quite emotional when they forget things or when they get frustrated or angry because they have forgotten things. | 124. | | | |
| | 125. | P5: Yea. The management here and the colleagues who are like higher up | | Feel well supported by management and colleagues |
| | 126. | than me... you can always go to them. They always give you the support | | |
| | 127. | that you need. They always have their doors open so that you can go and | | Sense of being able to seek support where you need it. |
| Can always go to management or higher up colleagues for support. They always have their doors open and will give you the support you need. | 128. | have a little chat with them. | | |
| | 129. | | | |

130. Interviewer: Yea. And do you ever have to seek support in any other ways?
131.
132. P5: What do you mean?
133.
134. Interviewer: I guess you said that you seek support from colleagues but do
135. you ever seek support from any other means?
136.
137. P5: I haven't personally because I haven't felt like I needed it. I have felt
138. like the support from everybody here is enough for me.
139.
140. Interviewer: Ok. Is there anything else that you would like to say about
141. things that you find difficult or things that you don't really like about
142. working with clients with dementia?
143.
144. P5: Erm... well there's nothing that I don't like about it. It's just like I said
145. before... like the emotional side of it sometimes and that's about it really.
146.
147. Interviewer: Ok. So my next question is about... one of the roles in
148. residential homes can involve end of life care and I wondered if that it
149. something that is relevant to you?
150.
151. P5: It is yes... yea.
152.
153. Interviewer: Would you be able to say a little bit about your experience of
154. it?
155.

I haven't felt
I have needed to
look support from
other means.
The support from
everyone at the
home is enough

There's nothing I
don't like about
working with
clients with dementia.
It's just the emotional
side of it sometimes
but that's about it.

Have felt
supported enough
by management
and colleagues
not to need
extra support.

? Other people
might seek
extra support
if they needed
it and I might
too if necessary.

Minimising the
negative side
of the work!

Has mentioned
things they
don't like but
overall states
there's nothing
they don't like.

Almost a sense
of being
defensive about
the work - trying
to create an
impression that
they like it all.

Positives
outweigh the
negatives?

End of life care
is very physically
and emotionally
draining

It's very rewarding
knowing that you
have helped them
to die how they
wanted

I don't think there
could be anything
worse than wanting
to die is a constant
way and then that
not happening

Try to ensure
someone is with
them all the time

It's very different
being involved in
end of life care.

It's quite hard
doing the end of
life care plans.

You have to ask
them questions
about what they
want before they
are at the end of life.

It can be quite
difficult to broach
the subject and
hard to talk about.

It's difficult when
you can see they're
in pain

You can see that
they are in pain
through their body
language which
isn't nice.

Even though you
know they have all
the pain relief they
can have you can
see they are in pain.

156. P5: Erm... it's very draining. Both physically and emotionally very draining.

157. Erm... oh... erm.... I don't know how to word it. It's... It's very rewarding as

158. well knowing that you've given them... how they want to die you've

159. actually given that for them. Because I don't think there could be anything

160. worse than wanting to die in like a certain way with certain people around

161. you do you know what I mean? And then that not happening. We try to

162. make sure there is somebody there with them all the time. Erm... yea....

164. Interviewer: How have you found being involved in it... in end of life care?

166. P5: Erm... it's.... very different. I don't really... it's sometimes... at the start

167. when you first start doing it like end of life care plans and that it's quite

168. hard sometimes. You have to ask them the questions and stuff before they

169. actually are at the end of life. So that can be quite difficult to broach the

170. subject of it to be able to actually ask them what they want when they're

171. about to do. So it can actually be quite hard to talk about it. Erm... I don't

172. know...

174. Interviewer: Ok. So is there anything about end of life care that you find

175. difficult?

176.

177. P5: Erm... when... when you can see they are in pain. Even though you've

178. got all the pain relief and that ready for them and you know that they've

179. got all the pain relief that they can have... you know the patches and stuff

180. like that and the drips and that... Erm... it's still not nice because you can

181. see it in their body language the pain that they're going through... it just

sense of pride
in caring for them
at the end of
their life
sense of achievement
knowing that you
have given them
the end of life
they wanted.

Different to
usual role?

Hard to bring
up the topic of
end of life with
clients when they
are not at the
end of their life

Quite hard to
have discussions
about their
mortality.
Projecting our
fears of death
onto clients?

Witnessing clients
in pain is
difficult.
? causes conflict
with usual role
as there is
nothing else you
can do

Normally do
anything possible
to support clients
but can't in this
instance.
Goes against
natural instinct.

Appendix Q

Emergent Themes for One Participant

| Superordinate Themes | Subordinate Themes | Examples from Participant Transcript |
|----------------------------------|-----------------------------|---|
| The importance of relationships | Knowing your client | <p>"Life history is just very important as well. Once you know their life history you can more or less... solve...you know you can calm them down and put them at ease" (P7, Lines 47-49)</p> <p>"I think just getting to know that person. I think if you treat each one as an individual and become part of their life" (P7, Lines 79-81)</p> |
| | Sense of attachment | "Treat them as you would your Mum and Dad" (P7, Line 45) |
| | Role of support from others | <p>"You can always go to your management and they can come and help" (P7, Lines 135-136)</p> <p>"Management are always there. You teammates are helpful. Families as well" (P7, Lines 208-209)</p> |
| Something special about the role | Feeling important | "A privilege. Definitely a privilege. When the family ask you to stay there... I'm welling up now... Sorry. [Becomes tearful]" (P7, Lines 184-186) |
| | Rewarding role | <p>"It's just making a difference. It's seeing them when they come in very frightened or scared. Or if we see them at night sometimes they can be scared because they have no concept of time. So you know the days can be very long. So they can be up all night and asleep all day and they can become totally confused when they see people eating breakfast and things like that. But it's just nice to reassure them and get to know them" (P7, Lines 91-96)</p> <p>"It's just more rewarding... the more you go on the more you learn, the more they trust you. The more relationships you build up" (P7, Line 318-320)</p> |

| | | |
|--------------------------|----------------------------------|--|
| | Commitment to the job | <p>"It can be tiring. It can be demanding but..." (P7, Line 54)</p> <p>"There's not many negatives to be honest. Nothing that can't be worked out" (P7, Lines 264-265)</p> |
| The other side of caring | Conflicts with usual caring role | <p>"The workload can be difficult. When you're full, you know, there's a lot of paperwork. And there's a lot of paperwork these days. It totally takes over everything" (P7, Lines 101-103)</p> <p>"Deterioration I don't like, obviously" (P7, Line 151)</p> |
| | Dealing with emotions | <p>"You have to have a thick skin because they can be very insulting... very insulting [laughs]. But you can't take it personally – they're scared" (P7, Lines 119-121)</p> <p>"It's just very rewarding. It's very amusing. They can be hilarious. It's sad. It's all different types of emotions" (P7, Lines 78-79)</p> <p>"Just lots of happy times... lots of sad times" (P7, Lines 245-246)</p> |
| | It makes you think | <p>"Scary. When you think what's ahead [laughs] and you think 'I wonder whether I'll ever end up like that. I wonder what my family would be like, my children, if I was like that.' It makes you think" (P7, Lines 224-226)</p> |